



Culturally Responsive Palliative Care



Culturally Responsive Palliative Care Strategy

2013 - 2015

Final Evaluation Summary

Funders: We acknowledge and thank the funders for their support for the project



Introduction

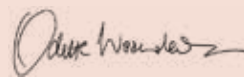
We are proud to provide this summary report on the evaluation of the first two years of Palliative Care Victoria's Culturally Responsive Palliative Care Strategy. The work we have undertaken in partnership in 2013-15 is an important step toward ensuring that all Victorians from culturally and linguistically diverse backgrounds have access to palliative care when and where they need it, so they are able to live, die and grieve well.

The Culturally Responsive Palliative Care Community Education Project is a partnership between Palliative Care Victoria (PCV) and the Ethnic Communities' Council of Victoria (ECCV) and, in the first year of the project, the Multicultural Centre for Women's Health (MCWH). The Project aimed to raise awareness of palliative care and palliative care services among culturally and linguistically diverse (CALD) communities, and to improve their access to culturally inclusive and responsive palliative care services.

The findings of the independent evaluation presented here show we have made positive progress in raising awareness of palliative care and its benefits among 10 culturally and linguistically diverse communities, as well as strengthening the capacity of over 400 palliative care staff and volunteers to provide culturally responsive palliative care.

We would like to thank the many people and organisations who have worked with us to deliver these projects, including the Multicultural Centre for Women's Health, the community organisations and members of the ethnic communities, palliative care services, Radermacher and Associates, Judith Miralles & Associates, the project team members at PCV and ECCV and the steering group. We would also like to thank and acknowledge the project funders: The Lord Mayor's Charitable Foundation, the Victorian Government, the Trust Company and Palliative Care Victoria.

It is important that we continue to work together to sustain and extend these achievements as part of our ongoing commitment to provide inclusive and culturally responsive palliative care support to all Victorians.



Odette Waanders
CEO

Palliative Care Victoria



Dr Irene Bouzo
Executive Officer

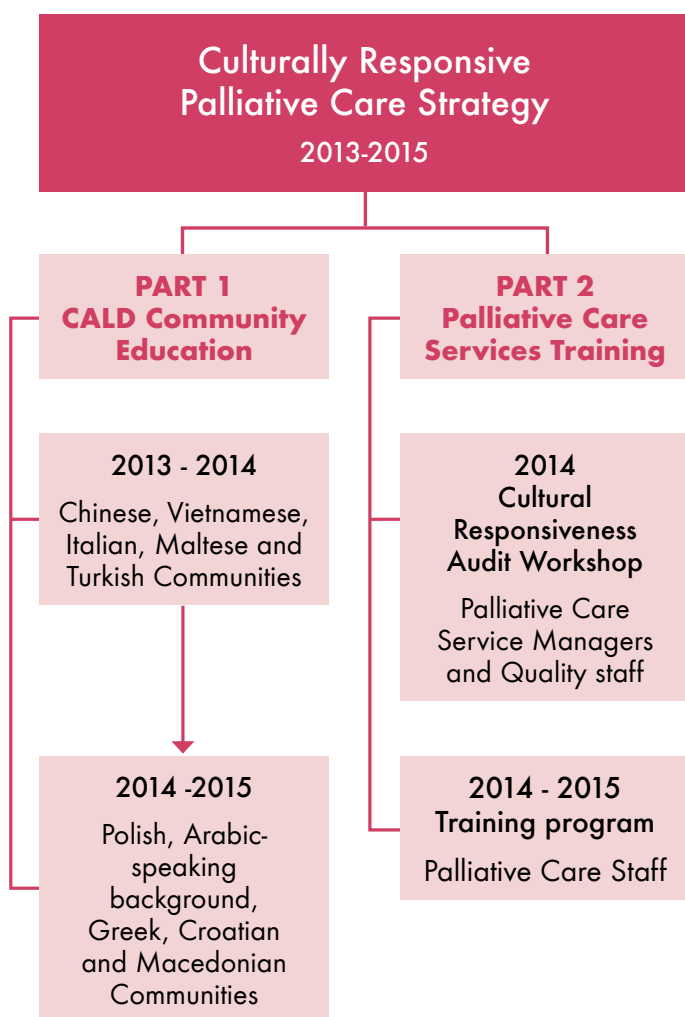
Ethnic Communities'
Council of Victoria



What were the aims of the Strategy?

- To overcome taboos, fears and stigmas surrounding death, dying and bereavement in the targeted CALD communities
- To expand understanding of palliative care in the targeted CALD communities
- To address concerns in the palliative care sector and CALD communities regarding the cultural responsiveness of palliative care

What were the key parts of the Strategy?



What did the projects deliver?

CALD Communities



Palliative Care Services



Background

Why were the projects necessary?

- There is a significant and growing CALD population in Victoria
- The percentage of the CALD population in older age groups is increasing at a faster rate than the increase in older age groups in the general population: 28% of the CALD population will be aged 80+ by 2026, compared with 22% of the wider population
- Low levels of English language literacy in older members of some CALD communities
- Comparatively low rates of use of palliative care services by people from CALD communities

How did the project partners plan and manage the projects?

- Consultative forums in 2010 and 2012 with people from the ethnic and multicultural sector, the palliative care sector, and other key stakeholders
- Formation in 2010 of a collaborative leadership group of 15 organisations including peak bodies and sector representatives
- Research including a literature review, interviews with key stakeholders, a survey of palliative care staff and the development of recommendations for the projects
- Service Agreements between Palliative Care Victoria (PCV) and the key project partners; Ethnic Communities' Council of Victoria (ECCV) (2013-15), the Multicultural Centre For Women's Health (MCWH) (2013-14), and Judith Miralles & Associates (JM&A) (2014-15)
- A Project Steering Group including the key partner organisations and other stakeholders drawn from palliative care services, palliative care consortia, other interested organisations and the Victorian Department of Health met regularly throughout 2013-15
- A community reference group for each of the ten communities provided invaluable advice, input and cultural expertise and each group met four times over a period of about six weeks



What resources did the projects develop?

- Ten peer education resources, tailored by and with each of the ten communities, which included specific information about culturally sensitive end-of-life issues and detailed modules for use in delivering a community education session about palliative care
- Bilingual information about palliative care, endorsed by each community reference group, translated into eleven languages (two Chinese languages)
- A communication toolkit for use by CALD community organisations, covering key messages, target audiences, media strategies, templates and FAQs
- Two training handbooks and a video clip used in the culturally responsive palliative care education program for the palliative care sector

“There is a significant and growing CALD population in Victoria”

Community Education Sessions to raise awareness of palliative care

Who came to the community education sessions?

Overall across all language groups:

- The majority of participants (68%) were women – ranging from 54% to 86% across language groups
- About half of the participants (55%) were over the age of 70, although this ranged considerably across language groups – from 11% in the Arabic-speaking background groups to 76% in the Italian groups



Did participants know about palliative care before the community education sessions?

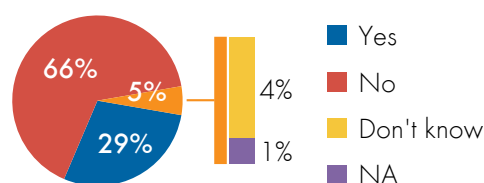
- An average of 66% of participants reported that they did not know about palliative care before the community education session but the level of awareness differed across the language groups



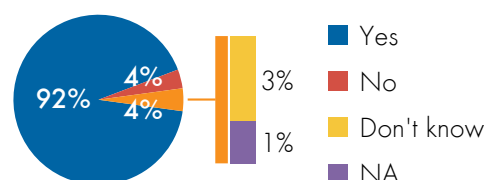
What were the key outcomes from the sessions as reported by the participants?

- A total of 3,214 participants completed an evaluation form and they told us:

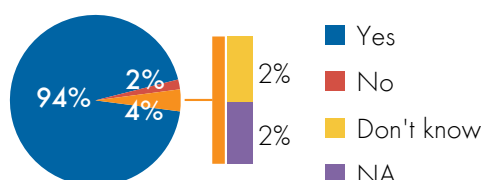
I knew about palliative care before today



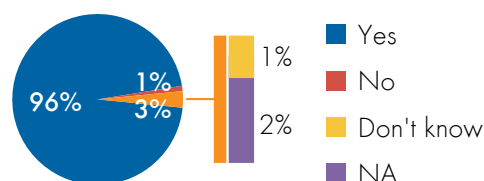
I learned new things today



I will tell friends and family about palliative care



I think palliative care is a good idea



- Despite 29% of participants indicating that they knew about palliative care prior to the session, 92% said they learned something new, so, although they might have heard of palliative care, they were not familiar with all of the details
- Apart from the variations in previous knowledge about palliative care, there was not a lot of variation in the responses for the other three indicators across the ten communities

What did people tell us after participating in the community education project?

"Prior to this reference group, this participant had not been aware that palliative care services could be delivered at home. She discussed with her parents the possibility of, when the time came, engaging such a service in order to help her care for them and they were agreeable to this prospect. She noted that his openness to this service may have been based on the understanding that this would be of benefit and support to her (his daughter and potential carer), making the idea more acceptable to him."

(Steering group member, 2014)

"I think this project has been very beneficial for me and for the communities I work with because patients need to know about palliative care and the services it can offer them. Information from the project has also changed the way in which I have discussions with my patients about having a life limiting illness so that I can be sure that they have understood what I am saying and what options they have. In one particular case I can think of, this caused some initial distress for the patient but two days later she made an appointment for her and daughter to discuss her end of life wishes and she has now been referred to a community palliative care service."

(A GP with a patient group that includes several of the communities included in the project, 2015)

"The launch actually made the whole difference. There was our Consul there ...people will remember that. There was something, not just information sessions. People they know, that they can see and meet - our Consul, our CEO, people from the Board, from the government because they've been funding the project, it was important for them all to be there."

(Community Reference Group member, 2015)

"The majority of people who I spoke to after the session were pretty interested in what was said and you can tell, they asked for more information, information sheets that were done in [community language] and English, not only for themselves but to give to friends and families that weren't there on the day. I've even had phone calls from people who attended, and they spoke to family about the information session, and they asked for more information sheets... the message did get out even to those who didn't, couldn't attend."

(Bilingual health educator, 2104)

"She [community worker] received a phone call after the interview [radio], and it was this guy who was unable to move from his bed, he was bedbound in his home, had no contact with services, he was highly isolated, severely depressed. He couldn't actually attend a community education session, and she took it on herself to call him and send out the actual brochures to him, mailed it out to him, and she said talking to him, he's actually decided to engage with those services and get some support to address his physical issues"

(Project worker, 2015)

"... when they [educators] provide health education about different things, breast health, heart health or cervical cancer, the stories about palliative care will come up, so they will be able to respond and address the issue of, the questions and comments that the educators had: 'Oh I wish I knew this 3 years ago' - now they know, now they know - and this is really a great asset, not only for educators, for the community, but also for palliative care services who will have their messages going across to the community and supporting community for a long time after the project is finalised."

(Palliative care sector worker, 2014)

Increasing the cultural responsiveness of palliative care services

What did the project do to improve the capacity of palliative care services to provide culturally inclusive and responsive services to people from CALD backgrounds?

- A high quality, tailored cultural responsiveness education program was offered to staff and volunteers working in palliative care services in Victoria
- Judith Miralles & Associates (JM&A) delivered two different four hour workshops between September 2014 and July 2015 in 19 metropolitan and seven rural and regional locations with attendees from 35 palliative care services:
 - » A State-wide workshop on *Conducting Cultural Responsiveness Audits* aimed at senior managers and quality managers with 26 participants
 - » 26 workplace-based sessions on *Delivering Culturally Responsive Palliative Care* with 349 participants
- Each workshop was tailored to meet the specific cultural responsiveness education needs of the palliative care service that was hosting the workshop
- Each workshop participant was provided with a training manual and free access, funded by the project for 2014-15, to CultureMate®, an online resource managed by JM&A

What were the responses of workshop participants?

Of the 420 workshop participants, 349 (83%) completed an evaluation form. Their feedback indicated:

- The workshop was excellent or very good (90%)
- The program was relevant to their work (96%)
- They were confident that they would be able to transfer what they had learned to their work (90%)

What did participants tell us after attending the cultural responsiveness workshops for palliative care staff and volunteers?

"As practitioners we are in such a hurry and we miss stuff because we don't listen... not everyone communicates the way we do. And they don't realise we're in a hurry. You just want the important information, we have to hear the whole lot....It was a wonderful training day so if it could happen again I'd fully support it."

"It's one workshop I certainly do remember. And I think the other thing is that she [the workshop facilitator] used some of the material of people who are very well respected in palliative care. So as soon as I saw that I thought, You've got the good stuff."

"It's really good to go back and have a look at it [the training manual], I was really impressed with it...I had a few [copies] that I've actually given to other people and they've been really impressed with it as well, just for the activities that were included there."

"A patient from Kenya was coming into our centre after her chemo sessions and just getting on to the site [Culturemate®] and typing in a few questions, I was able to get some references to pass on to her where there was a tiny group of those people who were in Melbourne that she could talk to. And the next time she came back to the centre she was a different person because she'd hooked up with some people she was able to talk to, and she actually bought one of them along who had good English. So yeah, it was helpful."

What were the key learnings from the work we have done so far?

- Participatory and engagement strategies are necessary to improve awareness of palliative care among CALD communities
- Fostering a conversation/discussion about palliative care is crucial and just making print resources available will not achieve this objective
- The participation of CALD communities in tailoring education and information to meet specific cultural, spiritual and linguistic needs is essential to ensure the resources meet the communities' needs
- The participation of palliative care services in project activities is valued and strengthens relationships of trust and understanding
- Long-term commitment and relationship development are the necessary building blocks to ensure community engagement and ownership
- Specific focus on the ongoing evaluation of the strength and health of the partnership by the partners is important when new partnerships are being developed and work is being done across sectors



“..strengthens relationships of trust and understanding.”

What are the recommendations to guide future work on continuing implementation of the Strategy?

- Ongoing mechanisms to collect, monitor and analyse data about activities related to palliative care from community and inpatient palliative care services and ethno-specific and multicultural community organisations are necessary to evaluate success of the Strategy over time
- The survey tool that replaces the Victorian Palliative Care Satisfaction Survey (VPCSS) must be accessible to people from CALD backgrounds and gather feedback from CALD patients, carers and bereaved carers about their experiences with palliative care services, including the way services respond to their cultural and spiritual needs
- For culturally responsive palliative care to become core business, and not just an add on, ongoing government support is required for both the ethnic community and palliative care sectors, not only in the form of ongoing funding but also in addressing prevailing structural barriers
- Follow-up or refresher sessions with the groups and communities and ongoing support for the workers in the key ethnic community partner organisations from 2013-15 will maximise the potential impact of the work undertaken to date and embed learning
- The co-development, implementation and evaluation of a multi-faceted continuing professional education strategy, which may include both online and face-to-face training about culturally responsive palliative care service delivery, will better meet the needs and preferences of the palliative care workforce
- Maintaining momentum and building on the groundwork that has been achieved to date will consolidate the awareness raising that has already occurred and the relationships and links that have been forged across the ethnic community and palliative care sectors



Who were the partners who worked together to implement the Strategy?



Palliative Care Victoria Inc (PCV) is the peak body representing palliative care providers, consumers and their families and those with an interest in palliative care in Victoria. We are committed to raising community awareness of palliative care and to build community capacity to deal with life limiting illness, death, grief and loss.

www.pallcarevic.asn.au



The Ethnic Communities' Council of Victoria Inc. (ECCV) is the Voice of Multicultural Victoria. As the peak body for ethnic and multicultural organisations in Victoria, we are proud to have been the key advocate for culturally diverse communities in Victoria since 1974. For 40 years we have been the link between multicultural communities, government and the wider community

www.eccv.org.au



The Multicultural Centre for Women's Health (MCWH) is a national, community-based organisation committed to the achievement of health and wellbeing for and by immigrant and refugee women. It is committed to ensuring a diversity of voices is represented in advocacy and policy development. MCWH provides health promotion and education following a feminist peer education model, delivered by respected and accredited bilingual educators.

www.mcwh.org.au



Community

Community partner organisation

Wave 1 (2013-2015)

| | |
|------------|--|
| Chinese | Chinese Community Social Services Centre |
| Italian | Co As It |
| Maltese | Maltese Community Council of Victoria |
| Turkish | Australian Turkish Association |
| Vietnamese | Australian Vietnamese Women's Association Springvale Indo-Chinese Mutual Assistance Association |

Wave 2 (2014-2015)

| | |
|----------------------------|--|
| Arabic-speaking background | Victorian Arabic Social Services |
| Croatian | Australian Croatian Community Services |
| Greek | Australian Greek Welfare Society |
| Macedonian | Macedonian Community Welfare Association |
| Polish | Polish Community Council of Victoria |

Radermacher and Associates

Judith Miralles & Associates

We would also like to thank and acknowledge the many people and organisations who have contributed to the success of these projects including the members of the Leadership Group, the Project Steering Group, the ten Community Reference Groups, and participating palliative care services and consortia representatives.

Where can I get copies of the full Evaluation Report?

- The Executive Summary of the report can be downloaded at http://bit.ly/CALD_2013-15_Final_Evaluation_Exec_Summary
- The full report (with appendices) can be downloaded at http://bit.ly/CALD_2013-15_Final_Evaluation_Report



Culturally Responsive Palliative Care

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