Informing a Palliative Care Cultural Responsiveness Strategy

May 2012

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Executive Summary

UltraFeedback was engaged by Palliative Care Victoria (PCV) on behalf of the Palliative Care Cultural Diversity Leadership Group¹ to inform a strategy to address the needs of culturally and linguistically diverse (CALD) communities across Victoria. The desired outcomes of the strategy are:

- Culturally inclusive, responsive and competent palliative care organisations and workforce.
- CALD communities are informed about palliative care.
- Improved utilization of palliative care services by CALD communities.

The research project aimed to identify key insights – comprising relevant research findings, relevant resources, relevant initiatives and opportunities – that will, in collaboration with key stakeholders, assist in developing and implementing key strategies and associated action plans for these three key result areas.

Overview of research methodology

The research was undertaken between December 2011 and April 2012. It comprised three key components:

1. A comprehensive literature review, including 54 references covering both Australian and internationally published literature².
2. The literature review informed the development of an interview guide, which was used in 28 key stakeholder interviews. The interviewees were from the following organisations:
   - Palliative care consortia
   - Palliative care services
   - Multicultural peak bodies
   - Government agencies
   - Ethno-specific organisations
   - Migrant resource centres
   - Carers Victoria
3. An online survey was designed to collect information from the identified service providers of Palliative Care services to CALD communities. A total of 89 individual survey responses were achieved.

Consultation

The research project was undertaken in close consultation with Pino Migliorino, Managing Director of Circa Research and Chairperson of the Federation of Ethnic Communities of Australia.

The Palliative Care Cultural Diversity Leadership Group functioned as the reference group for the project. It includes representatives from the following organisations:

Australian Multicultural Foundation
Calvary Health Care Bethlehem
Centre for Cultural Diversity in Ageing
Centre for Culture, Ethnicity and Health
Ethnic Communities Council of Victoria Inc
Healthcare Chaplaincy Council of Victoria Inc
Healthy Ageing Research Unit, Monash University

Palliative Care Team, Department of Health Victoria
Palliative Care Unit, Department of Health & Ageing
Palliative Care Victoria
Peninsula Home Hospice Service
Royal District Nursing Service
Southern Metro Region Palliative Care Consortium

¹ The Victorian Palliative Care Cultural Diversity Leadership Group was formed in December 2010 in line with the recommendation of the Ethnic Communities and Palliative Care Forum held in September 2010 to establish a leadership group and develop a strategy.
² A summary of the literature and resources survey will be published separately.
### Summary of Key Findings

<table>
<thead>
<tr>
<th>Key Finding</th>
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<tbody>
<tr>
<td><strong>There is a need for a structured cultural responsiveness framework</strong></td>
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<tr>
<td>- Palliative Care service providers and their staff recognise the importance of providing culturally responsive services. Some organisations are implementing strategies to promote this.</td>
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<tr>
<td>- However, structured frameworks and support mechanisms need to be developed and implemented.</td>
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<td><strong>Information about CALD profiles of palliative care service catchments should be used more to drive strategy</strong></td>
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<td>- Palliative care services generally have a good understanding of where and how to access information on the CALD profiles of their service catchment areas. There is an opportunity for services to further utilise this data for targeted promotions and/or development of culturally appropriate resources and to monitor palliative care service utilisation by CALD communities.</td>
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<td>- Working in partnership with ethno specific communities helps to understand cultural diversity and the needs of clients. There is an opportunity to further develop these relationships.</td>
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<td><strong>A strategic approach to developing a culturally responsive and diverse workforce is required</strong></td>
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<td>- A structured program of cultural responsiveness training would assist palliative care services to provide culturally responsive services.</td>
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<td>- There is scope for further partnering with multicultural and other organisations with specialist expertise in cultural responsiveness to enhance the cultural responsiveness of the palliative care workforce.</td>
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<td><strong>The accessibility of cultural responsiveness resources and training materials needs to be improved</strong></td>
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<td>- Palliative care staff/employees know where to access information in their organisations to improve their cultural responsiveness. However, access to a central online repository, such as that recently developed by PCV, will assist to improve access to a broader range of cultural responsiveness resources and information about palliative care in community languages.</td>
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<tr>
<td><strong>CALD populations should be included in research to inform clinical tools and best practice</strong></td>
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<tr>
<td>- This is needed to ensure that clinical tools and the development of best practice guidelines take account of cultural diversity and support the provision of culturally responsive care and services. This requires the inclusion of CALD populations in research and clarity about the characteristics of populations included or excluded from research studies.</td>
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### Key Finding

**Increased engagement and partnership with CALD communities would be beneficial**

- Given the number and diverse needs and situations of CALD communities in Victoria, it would be helpful to develop criteria that palliative care services can use in identifying which CALD communities in their catchment areas should be given priority in relation to engagement strategies to address low levels of awareness of and access to palliative care services, and to understand their needs for the provision of culturally responsive services.
- It is important that best practice approaches to engagement and partnership are utilised.

**Awareness and understanding of palliative care services in Victoria is low across the broader community**

- This presents a challenge for all services because services have a need to work within the community at large, as well as within the many cultural and linguistically diverse communities that exist within their catchment areas.

**Collaboration with other health care sectors would improve cultural responsiveness**

- Palliative care services are actively and strongly promoting services to healthcare and other "mainstream" organisations.
- While there is apparent potential and willingness for other organisations to work with palliative care services to raise awareness of palliative care, more emphasis on engaging with and promoting to ethno-specific communities is required.

**Language services and other strategies to address communication barriers are a priority**

- A culturally diverse workforce helps to improve the cultural responsiveness of an organisation. The recruitment of staff and volunteers who are bi-lingual has been found to be beneficial and can be facilitated through targeted recruitment and training strategies to specific CALD communities.
- There is an opportunity to foster effective working relationships with interpreters through staff training in this area.
- Increase the availability of palliative care information/resources in multiple formats. Audio and visual materials for raising awareness have been found to be effective and provide a better chance of processing information, particularly when literacy levels are low.

**There is a need to optimise existing resources and initiatives**

- Services reported having competing priorities and limited availability of staff to specifically focus on promoting awareness of palliative care and available services. This was reflected in little evidence of monitoring the effectiveness of communication or promotional strategies.
- Collaborative regional and state-wide strategies in the areas of engagement and partnership, promotion and cultural responsiveness training could help to optimise the effectiveness and efficiency of available resources and any new initiatives.
### Key Finding

**A need to increase engagement with primary health care providers to raise awareness and improve referral pathways to palliative care**

- Our findings support the need to engage with and educate primary health care practitioners about palliative care services. Barriers that were identified are: difficulty discussing death; the focus on curative treatment rather than preparation for end of life; and a general lack of awareness of the scope of palliative care services.

- There is an opportunity to enhance referral pathways through engagement with healthcare practitioners; further training and education for primary health care practitioners is needed.

- Further development of advance care planning may assist to improve awareness of, and referral pathways to, palliative care services.
Summary of Recommendations

Recommendation 1: Utilise a cultural responsiveness framework for palliative care services across Victoria

- Adopt and implement the Cultural Responsiveness Framework for all palliative care services and adjunct areas such as education, research, service planning and coordination. This would provide a consistent framework for use by all palliative care services and health services in Victoria.
- Ensure the use of this framework is recognised as core business and integrated into organisational governance, planning, community and consumer participation, communications, workforce training and development, service delivery and quality improvement processes.

Recommendation 2: Use information about CALD communities to implement the cultural responsiveness framework

- Access available data on community demographic profiles (including CALD) for each palliative care region and service catchment area in Victoria and update this as the 2011 census data becomes available from mid 2012;
- With reference to specific criteria, identify which CALD communities within the region / service catchment area are a priority for further engagement and partnerships so as to understand and respond to their specific needs;
- Monitor the utilisation of palliative care services with reference to the CALD profile of the catchment area and address identified opportunities to improve palliative care service utilisation by CALD communities.

Recommendation 3: Increase engagement and partnerships with CALD communities

- Palliative care services proactively engage and partner with specific CALD communities so as to understand their specific needs and to tailor consumer participation, promotion, service delivery, and quality improvement activities accordingly;
- Develop and maintain positive partnerships with identified CALD communities to improve their awareness of and access to culturally inclusive and responsive palliative care services.

Recommendation 4: Develop workforce capacity to provide culturally responsive palliative care services

- Ensure staff and volunteers receive structured training to develop and maintain their capacity to provide culturally responsive services;
- Utilise accredited translation and interpreter services in accordance with the Victorian Government language services policy and consider ways to provide palliative care information, pre-briefing, de-briefing and counselling to support interpreters perform their role in this context;
- Promote employment and training opportunities in the palliative care sector to CALD communities within the catchment area;
- Recruit staff and volunteers from CALD communities within the service catchment area, including bilingual staff.
Recommendation 5: Improve access by CALD communities to information about palliative care in community languages and in accessible formats

- Engage with CALD communities to better understand their cultural perspectives and any cultural sensitivities that need to be considered in relation to information about palliative care;
- Ensuring information is provided in accessible written, audio and visual formats with specific priority being given to identified gaps and opportunities for improvement;
- Consider regional and state-wide strategies to improve effectiveness, including access via an online repository of information about palliative care in community languages;
- Ensure any new information is developed with reference to cultural information and sensitivities and guidelines on effective communication with CALD communities and best practice examples.

Recommendation 6: Optimise resources through collaborative strategies to improve cultural responsiveness

- Identify and utilise opportunities to optimise the efficiency and effectiveness of available resources through collaborative strategies that will improve access to culturally responsive palliative care services. For example:
  o Utilise state-wide and regional strategies, where appropriate, to reduce the burden on CALD communities and individual palliative care services while still ensuring their participation;
  o Leverage existing networks and forums that promote healthcare services to CALD communities;
  o Utilise the services of multicultural organisations and other groups with specialised expertise in cross-cultural communications, cultural responsiveness training, language services, etc.;
  o Access resources available through relevant funded programs, such as the Community Partners Program, Local Palliative Care Grants Program, etc
  o Negotiate lead agency roles and areas of specialised expertise that will enhance the overall capacity of the palliative care sector in Victoria to provide culturally responsive services.
- Identify and record additional resource utilisation (financial and human) in providing culturally responsive services to CALD clients and their families / carers; this will assist in identifying ongoing funding requirements particularly in relation to activity based funding.

Recommendation 7: Engage with primary health care practitioners to facilitate referrals to palliative care

The outcomes of implementing a cultural responsiveness framework for palliative care services can be enhanced through parallel strategies to engage with primary health care practitioners. As a priority, consider strategies to engage with Medicare Locals and GPs to:

- Enhance awareness of palliative services;
- Enable informed patient decision making with respect to palliative care;
- Facilitate timely and effective referral pathways to palliative care.

Recommendation 8: Monitor and evaluate the effectiveness of strategies to improve cultural responsiveness

- Monitor and evaluate the effectiveness of strategies to improve the cultural responsiveness of palliative care services using processes that include opportunities for CALD / consumer participation. This includes strategies to improve awareness of palliative care among CALD communities, the utilisation of palliative care services by CALD communities; and the delivery of culturally responsive palliative care services. This should be an integral part of data collection, quality systems and improvement processes.
Section 1: A structured cultural responsiveness framework

A number of strategies have been utilised in Victoria to improve access to health and community services by CALD communities and to increase their cultural responsiveness. Experience has found that these are most effective when there is a clear rationale, the objectives are clearly stated, they are embedded into ongoing organisational systems and processes, they are formally linked to other complementary strategies and programs, and there is effective coordination, monitoring and evaluation.3

The following relevant structured frameworks are currently in use in Victoria:

1. Cultural responsiveness framework: Guidelines for Victorian health services

   This framework encompasses a strategic and whole-of-organisation approach and is designed to be aligned with health services’ strategic planning processes. It is based on the four key domains of quality and safety: organisational effectiveness; risk management; consumer participation; and effective workforce. It articulates six standards for culturally responsive practice and specifies key performance measures to improve cultural responsiveness over time. Reporting by health services against this framework commenced in 2010. This Framework currently applies to all hospital services in Victoria, including inpatient palliative care services.4

2. Strengthening diversity planning and practice: A guide for Victorian Home and Community Care services

   This Guide supports organisations to implement diversity planning and practice across the Home and Community Care Program by outlining key concepts, and providing information, resources and tools to plan for and improve service responses to diversity within each organisation’s catchment. Diversity encompasses a range of special needs groups, including people from culturally and linguistically diverse backgrounds. It supersedes the earlier cultural action planning approach and HACC-funded organisations are required to commence implementation of their first triennial diversity plans by 1 July 2012.5

As the Cultural Responsiveness Framework already applies to inpatient palliative care services within Victorian hospitals, it would be appropriate to adopt this framework for all palliative care services. There is scope to provide for a gradual implementation and adaptation to address the specific needs of smaller community palliative care services.

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3 Effective Change Pty. Ltd, and Department of Human Services, Aged Care Branch (2009) Evaluation of the Home and Community Care Program Cultural Planning Strategy, Rural and Regional Health and Aged Care Services, Victorian Government, Department of Human Services, Melbourne, Victoria

4 Department of Health, Cultural Responsiveness Framework: Guidelines for Victorian health services, Rural and Regional Health and Aged Care Services, Victorian Government, Department of Health, 2009

5 Department of Health (2011) Strengthening diversity, planning and practice: A guide for Victorian Home and Community Care services, Victoria
Section 2: Cultural responsiveness and palliative care

Cultural responsiveness and palliative care

Culture plays a critical role in how patients, carers and families view and make decisions about treatment options and delivery of care. The lack of awareness of cultural and spiritual views and beliefs, and the lack of knowledge and experience in working with those from diverse cultural and spiritual backgrounds, can have a significant impact on discussions about the identification of appropriate treatment options and delivery of care.

Lickiss (2003) raises the importance of the wide variations between and within different ethnic groups. According to Lickiss, “a person originally from one ethnic group may conform a little or totally to the current customary expectations of that group, either in the country of origin or in contemporary Australia. Individuals are embedded in culture, but cultures are, in turn, embodied in people who are evolving in response to environmental as well as hereditary stimuli, and sometimes finding cultural expressions at variance with those of previous generations.”

Therefore, the task of delivering care to patients from diverse cultural, religious and spiritual backgrounds requires the healthcare practitioner to identify and deliver tailored care to the individual (specific), which may or may not be the same as the care plan that would be delivered with reference to that individual’s cultural background or heritage (general).

Terminology

Cultural Competence is defined as “a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals; enabling that system, agency or those professionals to work effectively in cross-cultural situations.”

Other authors have proposed that cultural competency includes: (a) knowledge and experience working in cross-cultural situations, and (2) possessing and using culture-specific knowledge and experience. Culture-specific knowledge is a basis for beginning the exploration of individual or family beliefs.

The evolution from “awareness” (knowledge) to “cultural competence” (behaviour) in Australia has been previously reviewed, where the authors summarised that cultural competence is required to address the needs of three main stakeholders:

- CALD clients of an organisation;
- CALD employees of an organisation;
- Non-CALD employees of an organisation.

In 2009, Farrelly and Lumby attempted to identify examples of cultural competence best practice in Australia by reviewing the published literature and cultural competency training programs. The authors found that despite...

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the popularity of past “Cultural Awareness Training” as a means to achieving culturally appropriate service delivery, there has been relatively little systematic evaluation of its potential impact. The authors also found it difficult to determine what aspects of such training are resulting in successful outcomes, and which approaches are more effective, due to the variation in training.

**Cultural responsiveness** refers to “health care services that are respectful of, and relevant to, the health beliefs, health practices, culture and linguistic needs of diverse consumer/patient populations and communities. That is, communities whose members identify as having particular cultural or linguistic affiliations by virtue of their place of birth, ancestry or ethnic origin, religion, preferred language or language spoken at home. Cultural responsiveness describes the capacity to respond to the healthcare issues of diverse communities. It thus requires knowledge and capacity at different levels of intervention: systemic, organisational, professional and individual.”

The terms cultural competency and cultural responsiveness are essentially interchangeable. There are useful cultural competency tools available that can be used alongside the Cultural Responsiveness Framework.

**Patient-centred care and cultural responsiveness**

Australia (Victoria in particular) is truly multicultural. And with an ageing population the healthcare sector requires not only an awareness and understanding of cultural diversity, but also strategies to engage and tailor specific and effective cross-cultural treatment and care interventions.

A ‘flexible, patient centred’ approach was reported in most of the qualitative interviews as being important in the development of cultural competency.

Lickiss (2003)13 raises the importance of the wide variations between and within different ethnic groups. According to Lickiss, “a person originally from one ethnic group may conform a little or totally to the current customary expectations of that group, either in the country of origin or in contemporary Australia. Individuals are embedded in culture, but cultures are, in turn, embodied in people who are evolving in response to environmental as well as hereditary stimuli, and sometimes finding cultural expressions at variance with those of previous generations.”

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Palliative care staff can strive to be flexible, but without the necessary resources to support the wishes of the patient, it may be difficult to do so. Two quotes from the palliative care sector illustrate this below:

- “When patients die from cultural backgrounds where it is considered normal to wail at the grief phase it can be very distressing for other patients...there were some measures talking with community leaders...you have this real clash of needs...do services need to evolve, build appropriate facilities that give the patient a private space”
- “One of my uncles wanted to get into the Chinese specific nursing home, not because of his language barrier, because he was second generation, but more simply, it was because of the food.”

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12 Ibid, p12.
Section 3: Strategies to develop the cultural responsiveness of the palliative care workforce

Measure and profile local and specific CALD communities

An important first step in working to develop cultural responsiveness is to develop an awareness of the different cultures, religious and spiritual beliefs of patients, carers, families from specific CALD backgrounds within the service catchment area, as well as that of employees involved in the delivery of healthcare including palliative care services.

Data is available on the profile of CALD populations in capital cities and regional areas, and in local government areas (LGA) 14. The overwhelming majority of Victoria’s CALD populations reside in greater Melbourne. A few LGAs have substantial concentrations of CALD populations, with large numbers of people forming a large number of communities. However, the outstanding characteristic of the distribution of the CALD populations is its wide dispersion, with all LGAs having some representation of almost all CALD communities.

The main implication of this pattern is that enhancing access to community care services for CALD clients is a concern for all LGAs. A variety of strategies will be needed to respond to the needs of different communities of different sizes in different LGAs.

The geographic variations in the profiles of CALD communities give rise to two challenges:

1. It may be more difficult for ethno-specific agencies to reach members of their respective communities who are spread across many LGAs than it is for any Council to respond to the cultural diversity of communities within its own boundaries;
2. It may be easier to respond to the needs of large numbers of CALD clients in many metropolitan LGAs than to respond to the needs of very small numbers in rural and regional areas.

The extent to which palliative care services are profiling their clients was explored in the qualitative interviews and measured in the quantitative survey.

A very common response during our stakeholder interviews to the question, ‘where do you access the CALD profile of your patients?’ was that the information about specific CALD populations within their area is available on their local government area (LGA) website. All 11 services interviewed were aware of this. Only a handful of palliative care services interviewed were able to explain how this information was being utilised.

Our survey of the Victorian palliative care sector revealed that 60% of services review data on the cultural profile of their clients. Of those that reported reviewing the cultural profile of their clients, 70% (38 individual services) described how they utilised the data; open text responses have been grouped into the following themes:

- For general planning (30%);
- Development of translated material/ resources (including planning for interpreters) (16%);
- Reporting and funding requirements (13%);
- Planning for engagement with community groups (11%);
- Planning CALD specific staff training (11%);
- Develop a general awareness of the CALD profile (1%);
- Not sure/ don’t have enough CALD population to utilise the data (18%).

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We found that whilst all services are aware of where to access the CALD profile of their catchment area, they are not all using the information to drive strategic direction or to monitor service utilisation.

**Structured cultural responsiveness training and evaluation**

Cultural responsiveness training – specifically the development of general and specific knowledge, skills, experience and behaviours – is critical in delivering care to patients from diverse cultural, religious and spiritual backgrounds.

Training is offered through various organisations such as the Centre for Culture Ethnicity and Health, the Centre for Cultural Diversity and Ageing, and the Australian Multicultural Foundation. However, it appears palliative care services and their staff and volunteers could make more use of these training opportunities.

Similarly, ECCV can guide interested organisations on where to find information that is culturally specific, or where to access training. Ethno specific organisations can also assist with training for specific cultures, but they may need to be resourced in some way (needs to be targeted to the service’s CALD profile).

During the qualitative interviews, palliative care services reported the need to be active in the search for training, suggesting that there would be benefits in arranging a structured program of cultural responsiveness training to the sector. It is also apparent that there is a need for cultural diversity training that includes palliative care specific examples and scenarios, for example:

“Training has to be more directed to palliative care specifically. In the meantime, Palliative care services have to look out for what is already done for cultural competency in other services, for example maternity wards at hospitals” – Department of Health

**Level of cultural responsiveness evaluation among Victorian palliative care services**

Survey respondents were asked to what extent their organisations evaluate cultural competency. Figure 1 below indicates that there is scope for further improvement in this regard.

![My organisation evaluates its employees cultural competency](image)

Figure 1. Level of cultural competency (responsiveness) evaluation by palliative care services

Palliative care service providers and their staff recognise the importance and need to develop cultural competency and some organisations are endeavouring to address this themselves. However, structured frameworks and support mechanisms need to be developed and implemented. The NRFRACP reviewed national and international cultural competency training programs and identified the following best practice principles, based on their extensive review:\(^\text{15}\):

\(^\text{15}\) National Rural Faculty, Royal Australian College of General Practitioners (2004). Review of cultural training for GPs working in Aboriginal and Torres Strait Islander health (http://www.racgp.org.au).
• Genuine partnership that acknowledges principles of self-determination, community control, cultural respect and reconciliation;

• Genuine partnership that involves collaboration in the planning, implementation and evaluation of cultural programs and also local community involvement to ensure credibility and relevance of responsiveness training;

• Planning of training such that definition of goals and outcomes of responsiveness training inform program development and evaluation and principles of adult learning are respected;

• Delivery of responsive training which ensures:
  o Core content includes historical, cultural, socio-economic factors underpinning health and wellbeing, cross-cultural communication and cultural safety;
  o Learning environments provide for positive and safe interaction;
  o Multiple learning techniques are used;
  o There is a focus on behaviour change;
  o Flexible delivery of cultural training which can be locally adapted;
  o A realistic timeframe is allowed;
  o Training and ongoing support is provided for responsive training trainers and orientation and support for local community representatives

• Effective evaluation of responsiveness training, including long term impact and monitoring.

An example of cultural responsiveness training and evaluation

The Centre for Culture, Ethnicity and Health provides cultural competency training based on an American model. They also audit services using the seven domains of cultural competency. Cross et al (1989, cited in Ethnic Communities’ Council of Victoria, 2006) state that cultural competence is a complex framework, and that there is a tendency for systems and organizations to want a textbook solution, a quick fix, a recipe, or a “how to”, step-by-step approach. It is helpful for systems and organizations to conduct self-assessment and use the results to set goals and plan for meaningful growth. The NCCC described a system of organizational characteristics that may be exhibited at various stages along the cultural competence continuum.

The Centre for Culture, Ethnicity and Health is able to review cultural competency with agencies/services upon request; they are also working with the University of Melbourne to develop it into a self-audit tool which can be used for action plans.

“Training shifts people into thinking about diversity in a positive way. Simple to address with training”
– Ethno-specific agency

“Evaluations of cultural competencies can be done by introducing different scenarios, and asking how they will react. But this isn’t being done well, if at all”
– Palliative Care Service Provider

Access to resources and information for palliative care workforce

Our survey of Victorian palliative care services found that palliative care services:

- Know where to access information in their organisations to improve their cultural responsiveness, however, they would like access to further and additional information;
- Would prefer not to be told ‘what to do’, rather how to do it;
- Wish to receive further training in how to work with interpreters, including the establishment of formalised process for briefing and preparing interpreters (working with interpreters is discussed in more detail later).

Palliative care staff want further training

When asked to agree with the statement ‘I would like to receive further training in palliative care,’ the overall response from survey respondents was positive (average rating = 4.07, where 1 = Strongly Disagree, and 5 = Strongly Agree). That is, there is a willingness and interest in further training in this area.

When asked to identify what they thought were the most effective modes of training (where 1 = Not Effective at all and 5 = Highly Effective), survey respondents indicated the following preferences:

1. Face to face with external organisations (average rating = 3.84);
2. Face to face training with ethno specific community groups/ advocates (average rating = 3.82)
3. In house training (average rating = 3.63).

The least preferred option was online training (average rate = 2.81); however, quantitative results showed the majority of regional services had a greater preference for online training compared with metropolitan regions. This is not surprising, given it would be more difficult for services to access face to face training in regional areas.

At the same time, there is much anecdotal evidence to suggest limited access to training opportunities and capacity to attend contribute to low overall uptake. Frequency of training was asked of survey respondents to quantify this. Results showed that 46% of employees from palliative care services were offered cultural diversity training in the past 12 months, and only 29% of employees in fact attended training.

Develop partnerships with community and ethno-specific groups

In 2004, the National Rural Faculty, Royal Australian College of General Practitioners (NFRACGP)18 conducted an extensive review of national and international cultural competency training literature and concluded that one principle of best practice in cultural competency training is the development of genuine partnerships with local community groups. The partnerships described involve collaboration in planning and the implementation and evaluation of cultural competency training programs – including local community group involvement to ensure credibility and relevance.

The NRFRACGP found that the establishment of local community partnerships can help ensure that cultural competency training programs are not only addressing the needs of the organisation and the staff, but of the local CALD communities utilising its services.

The Healthy Ageing Unit at Monash University, in collaboration with the Ethnic Communities’ Council of Victoria and the Southern Metropolitan Region HACC Cultural Diversity Network, conducted a multi-stage project to deepen understanding of the nature of inter-organisational partnerships within the ethnic and multicultural aged care sector. The resulting report19 provides insights into benefits and limitations of partnerships, factors influencing partnerships and the characteristics of positive partnerships. It highlights the need to avoid top down planning and to be mindful of differences in power and resource capacity so as to promote positive partnership dynamics.

Interviews with key stakeholders also found concurring views and perspectives; below are selected quotations that illustrate the importance of developing genuine partnerships:

- “Working in partnerships with ethno specific agencies opens the doors for other activities and helps to de-mystify palliative care” – Palliative Care Service
- “Language will be a huge issue, but can be overcome by developing partnerships with ethno specific agencies...not just by working collaboratively with these services.” – Ethno Specific Agency
- “The Migrant Information Centre are like a case worker – they are quite aware of what we do and are able to promote our services” – Palliative Care Service

**Creating a culturally and linguistically diverse workforce**

Employing staff and volunteers who are bi-lingual is a strategy used by a minority of the palliative care services that were interviewed. The Ethnic Communities’ Council of Victoria’s Ageing and Cultural Diversity Strategy 201120 recommended that the Victorian Government should provide incentives for the recruitment, training and retention of bi-lingual staff in aged care. They noted that this is essential in maintaining a culturally responsive aged care workforce: “overseas qualified nurses and care staff from predominately non-English speaking countries bring valuable diversity skills to the aged care industry. Cultural awareness training for local staff and newcomers would improve their workforce transition into the Australian system. There is also a growing untapped market of multicultural Victorians who are attracted to targeted aged care training programs delivered through certified Registered Training Organisations in ethnic and multicultural agencies.”

In an interview with the Ethnic Communities’ Council of Victoria (eccv), it was noted that the recruitment of bilingual staff and volunteers would be a very worthwhile initiative for palliative care services to adopt. A handbook for bilingual people considering a career in aged care was developed by eccv.21 Likewise, the Centre for Culture, Ethnicity and Health published a report that included a set of guidelines to assist Victorian Government departments and funded agencies in the recruitment and employment of bilingual staff.22

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21 Ethnic Communities’ Council of Victoria (2007) Caring for your Community- A career in Aged Care for Bilingual Staff.
The challenge with managing bi-lingual staff is to ensure that they do not end up spending the majority of their time translating or interpreting, so that they can focus on performing the other elements of their role.

**Develop processes and procedures for effective partnership with interpreters**

As can be seen in Figure 2 below, overall use of interpreters by palliative care services appears to be quite low (which also reflects the lower utilisation of these services by people from CALD backgrounds).

The most common challenge for all 11 palliative care services interviewed was working with interpreters. Some of the most frequently cited reasons include:

- Patient refusal to work with an interpreter;
- Access and availability of interpreters;
- Use of appropriately skilled interpreters.

**Patient refusal to work with an interpreter**

Palliative care services indicated that refusal by the patient (or carer or family member) to work with an interpreter was common. Despite this being inconsistent with the Victorian Government policy regarding language services, it is a reality that all palliative care services face. Specific reasons for refusing to work with an interpreter included:

- Privacy issues: in smaller communities, sometimes the interpreter can know the family already;
- Not wanting to let a stranger into their home;
- Not wanting to talk about personal issues with a stranger.

A study conducted by the Centre for Culture, Ethnicity and Health (2006) analysed how CALD consumers access and use language services. They found that even though there was a preference to use a professional interpreter, participants usually, but not always, chose to use family to interpret. The key reasons include:
• Not being provided with interpreting services;
• Having to wait too long for interpreting services;
• Feeling uncomfortable asking for an interpreter;
• A fear that language services would be unreliable, delayed or inadequate.

While most participants highly valued the support of their families, they often described communication facilitated by family as limited or compromised. For other participants, the option to use family to interpret was not available. This was particularly the case for participants from newly arrived communities who often had no English speaking family members and sometimes no families at all.

The following quotations from the qualitative interviews demonstrate these challenges further:

• "I had a conversation last week and the patient wanted her granddaughter to be an interpreter. I said to her, that may be difficult for you, and she said, it’s not as difficult as having a stranger telling me"
• "Families can be non-compliant [in using an interpreter], and we can’t make them"
• ". . . they can sometimes have experience with bad interpreters and don’t trust the quality, they may know the interpreter so there are issues of privacy, part of the role of the interpreter is to abide by professional rules and that could be explained."
• "It’s quite common for them to choose not to have an interpreter"
• "Many cultures, many people, will not let us let a professional interpreter into the home, for that reason"
• "Sometimes in some languages there just aren’t any professional interpreters. Sometimes, the ones that you can find are their cousin, or brother, which creates problems with privacy."

Access and availability of interpreters
Availability and access to interpreter services are major issues for palliative care services. It was reported in the qualitative interviews that service providers may face difficulties in finding a face-to-face interpreter in the appropriate language, and/or dialect. Other reasons include:

• A shortage of skilled interpreters in the region;
• Timing – they can sometimes miss appointment times and to reschedule is difficult;
• In smaller communities with small populations, it has been reported that there may be a link between the family/friendship group and the interpreter. This may cause resistance due to a perceived lack of confidentiality.

Northern Health and Western Heath, whose regional catchment areas include a large proportion of CALD clients, have both demonstrated the effectiveness of having readily available in-house translators.

A similar but related issue here is funding. When asked to describe any specific problems or gaps with access to interpreters or information in community languages, the followed selected open-text responses were recorded in our survey of palliative care services:

• “Funding for interpreters runs out for us very quickly due to the increasing demand for this service”
• “Sometimes can be lack of funds for interpreter service”
• "Lack of adequate funding to always have professional interpreters in homes. Lack of adequate interpreters - poor interpreting skills, poor English language skills of the interpreters and lack of understanding by the interpreters regarding medico-legal issues”
• “Funding for interpreters is an issue for services who use interpreters regularly.”
Use of appropriately skilled interpreters

When discussing the use of interpreters in delivery of palliative care services, the issue of interpreter skill and experience in dealing with palliative care related situations is a major issue. From our stakeholder interviews and survey of Victorian palliative care services it is evident that palliative care is a sensitive area for interpreters to work in. It is not surprising that it has been reported that some interpreters find it very difficult and confronting to discuss issues surrounding death and dying.

Working with interpreters who lack the appropriate skills and experience highlights two areas of practical concern for effective palliative care service delivery. Firstly, the interpreter may require de-briefing and counselling if not appropriately prepared for the experience. Secondly, the interpreter may not directly translate phrases if they feel uncomfortable doing so, and the palliative care worker will not be aware of this.

Despite there being various skill levels of interpreters, palliative care specific training should perhaps be considered. Another strategy to address this barrier was mentioned in an interview with the Ethnic Communities Council of Victoria. That is, to provide a pre-briefing session for the interpreter to ensure that they are informed about the context of the appointment. An article is available in ECCV’s magazine, ‘Golden Years’ about best practice for briefing interpreters. The Royal District Nursing Service (RDNS) is developing a set of translation standards for working with interpreters.

Ensure clinical tools are validated for use with CALD patients

The issue of the lack of research involving patients and carers from CALD backgrounds was identified in interviews with key stakeholders as a factor impeding the provision of culturally responsive palliative care services. It was noted that the majority of clinical tools have not been tested and validated with CALD populations. This highlights the importance of ensuring that research and the development of clinical tools takes account of cultural diversity so that resulting clinical tools and best practice guidelines support the provision of culturally responsive palliative care services.

Section 4: A Community Informed About Palliative Care

This section presents evidence derived from the literature review, in-depth stakeholder interviews and the survey of palliative care services that provide insights into (a) current levels of awareness of palliative care, particularly within CALD communities, (b) the key barriers to awareness of palliative care, and (c) strategies to promote and increase awareness of palliative care.

Awareness of palliative care services among CALD communities

According to the 2006 Community Attitudes Towards Palliative Care Issues Project, commissioned by the Palliative Care Section of the Australian Government Department of Health and Ageing, 84% of Australians had heard of the term “palliative care.” Specifically:

- 13% had heard of the phrase, but did not know what it meant;
- 33% knew “a little bit” about palliative care;
- 38% knew what palliative care was and could explain it to someone.

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In 1998, a survey of 3000 South Australians found that 52% of respondents had an awareness of palliative care, whereas only 37% of respondents born outside of Australia had an awareness of palliative care.\textsuperscript{26}

The 2006 Community Attitudes Towards Palliative Care Issues Project also found that some respondents (and particularly younger respondents) indicated that although they were aware of the existence of such services as care for the terminally ill, care for the elderly, in home care, and pain management, they did not necessarily associate these services with “palliative care.”

The level of awareness and understanding of palliative care services among the general population is low to moderate at best, and likely to be even lower again among members of CALD communities. This view was unanimously shared among all the 28 stakeholders interviewed. For example, one migrant resource centre representative interviewed was not aware that palliative care could be provided in the home.

In stark contrast to this lack of awareness is the projection that by 2026 nearly one in every four people aged 80 years or older will be from a CALD background.\textsuperscript{27} In view of this, it is imperative to promote awareness of palliative care among local and CALD communities, as well as healthcare practitioners (to be discussed in section 5) to improve understanding of services and enhance referral pathways.

**Barriers to awareness of palliative care among CALD communities**

Our survey of 89 respondents from within the Victorian palliative care sector found the lack of awareness of palliative services to be the most significant barrier limiting the use of palliative care services by people from CALD communities (55% of respondents chose this as one of the top three most significant barriers). These findings are consistent with previous research which has identified lack of knowledge or misconceptions about palliative care, cultural differences in perceptions about death, and language and communication issues as major barriers to awareness.\textsuperscript{28}

A summary of the barriers to awareness of palliative care is presented in the table below.

\textsuperscript{26} Taylor, A. Box, M, (1999). Multicultural Palliative Care Guidelines, p7.


## Summary of barriers to awareness of palliative care services among CALD communities

<table>
<thead>
<tr>
<th>Barrier to awareness of palliative care services</th>
<th>Description / Explanation</th>
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| **Difference in perceptions of death and difficulty in discussing death** | There is a view that the concept of palliative care is either unknown, misunderstood, or that there is reluctance within the community (as a whole) and the medical profession to talk about death and dying. For example, in general, it has been found that Asians may view death and other health related decisions as family matters, in contrast to Caucasians who may value individualism and autonomy.  
This view was strongly shared among stakeholders we interviewed from within the palliative care sector in particular. Below are some quotes that illustrate this:
- “[Lack of] preparedness to entertain that they might need palliative care. Reluctance of doctors to give serious thought to raising palliative care until it is too late.”
- “[Patients] not wanting to talk about death, reluctant to think about dying” |
| **Negative, feared or absent image of palliative care** | General lack of awareness and understanding of palliative care. Sometimes, no translation exists for the term “palliative care.” There may also be misperceptions about what is required to access palliative care, for example, the amount of forms to fill out or the type of information requested may be perceived as intrusive. |
| **Language and communication** | In addition to low familiarity with the service system, there is also a lack of information in the preferred community language. However, the solution is not simply translation of communication into other languages (or the use of interpreters), but rather effective interpretation of the key concepts underpinning palliative care – a view shared across all multicultural peak organisations. |
| **Fear of treatment and side effects** | A lack of understanding of pain relief, fear of the administration, side effects and ramifications of medications. |
| **Limited targeted promotion of palliative care services to CALD communities and via ethno-specific media** | Services are promoting palliative care to various organisations, but limited work is being targeted towards ethno-specific communities. |

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**Strategies to raise awareness of palliative care**

This section presents strategies to raise awareness of palliative care as identified in the literature review, stakeholder interviews and survey of Victorian palliative care services.

**Engage with ethno specific communities in identifying palliative care needs of CALD communities**

Our survey of the Victorian palliative care sector found palliative care services are actively and strongly promoting services to healthcare and other “mainstream” organisations; however, it is apparent that greater emphasis on promotion and engagement with ethno-specific communities is required.

For example, of those we surveyed, 68% indicated that their services are engaging with other mainstream organisations (e.g. aged care facilities) and primary health care practitioners and/or related associations to promote their palliative care services. However, only 30% of services are working with multicultural organisations and peak bodies, 14% with migrant resource centres, and 13% with established ethno specific communities.

When survey respondents were asked which promotional activities have been conducted in the past 12 months, the most selected options were:

- Networking through health related conferences (67%)
- Public forums specific to palliative care (54%)
- Printed materials displayed at hospitals (52%)

In comparison, the least selected options related to ethno-specific media and networking:

- Ethno-specific radio (4%)
- Ethno-specific newspapers (5%)
- Information sessions to existing ethno specific community groups specific to Palliative Care (13%)

Overall, this finding indicates palliative care services are focusing the majority of their promotional activity toward the general population. Whilst it is important to focus efforts on raising awareness within the general population, more effort is required to engage with ethno specific communities.

**Work in partnership with specific ethnic communities**

Palliative care services, multicultural peak bodies and ethno-specific organisations need to work together in partnership to address the health care needs of ageing CALD populations in Victoria. This is consistent with the notion that health issues cannot be tackled by relying solely on individual organisations, but are best addressed in partnership with community leaders and those that provide guidance and influence.

This view was reflected in interviews with the palliative care sector and ethno-specific agencies, as illustrated in the following quotations:

“**We have an ambassadors program with volunteers presenting to clubs, like seniors clubs, to talk about palliative care...it has been really successful...you can see a huge change where people begin to grasp what it [palliative care] really means**”

– Palliative Care Service Provider

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“Working in partnerships with ethno specific agencies opens the doors for other activities and helps to de-mystify palliative care” – Palliative Care Service

“Language will be a huge issue, but can be overcome by developing partnerships with ethno specific agencies...not just an MOU but working collaboratively with the services.” – Ethno specific Agency

“The Migrant Information Centre are like a case worker – they are quite aware of what we do and are able to promote our services” – Palliative Care Service

Interestingly, other authors have reported a preference to engage with individual members of CALD communities in “restaurants, laundries, and the like” over community centres and churches (locations where these communities gather) to obtain information about their specific needs. For example, one author has found the less formal contacts to be more open and receptive to talking about their specific cultural beliefs and needs. In contrast, Kemp describes those from community centres and churches as being more likely to have an agenda of promoting their particular organisation or perspective, which may not necessarily be reflective of those within the community.

Although this viewpoint provides an interesting counterpoint, overwhelming research and anecdotal evidence tends to highlight the importance and value of engaging with key leaders:

“Five years ago we met with key leaders in the Vietnamese community to raise awareness of our service...it gave us a better understanding of the challenges in raising awareness in this community.”

– Palliative Care Service

Our survey of the palliative sector captured similar insights. When asked if ‘reluctance of other organisations to work with them’ is a barrier to raising awareness for palliative care services, the overall response indicated this was not a major barrier (average rating = 1.95, where 1= Not a Barrier, 5= To a Great Extent). This indicates that other organisations are willing to work with palliative care services and, in combination with the evidence of the efficacy of a joint approach, strongly suggests that community partnerships are an invaluable way to raise awareness of palliative care.

**Increase active and targeted promotion of palliative care services to local and CALD communities**

Ethno specific communities that were interviewed did indeed express an interest in working with palliative care agencies to raise awareness of services. The barrier that was identified by a handful of interviewees with ethno-specific communities is competing priorities (i.e. other programs for example sexual health or gambling that are currently being undertaken).

These findings may reflect limited staff and resources, and lack of demand from members of CALD communities. Nonetheless, there are strategies that can help to improve utilisation of palliative care services. For example, during an interview with the Maltese community representative, it was suggested that the best way to promote services is to work with an advocate in the promotion of palliative care, whether it be a priest or a key opinion leader within that particular community. This view was also shared in a separate interview with the Macedonian Community Welfare Association. Use of a peer leader model in a health promotion context has been proven to be successful for the Maltese in a campaign to raise awareness about gambling.

Another successful initiative described by community groups and the palliative care sector was the use of speakers at various community forums and presentations. Ethnic communities that were interviewed are...

currently conducting sessions to cover a range of topics: carers; gambling; sexual health; dementia; vision impairment; and residential aged care.

The following tips were noted in planning for a successful presentation.

- Participants are more interested when they can relate to someone;
- Presentations should not exceed 30-45 minutes, any longer and participants will get bored;
- If the forums are attached to other existing activity sessions that are being conducted, there is no need to recruit participants.

Other suggestions included:

- “Increased resources and advertising for CALD communities”
- “Advertisement in CALD specific publications”
- “Information provided at doctors and hospitals - usually places of trust. Also information provided to other organisations to be incorporated into information handed out, e.g. to Aged Care Facilities. Enhance collaborative work.”
- “Development of culturally sensitive translated information that could be available in community health centres and at GP practices - providing access details about palliative care services.”
- “Ensuring referrals are timely to enable face to face interpreters to be located”

**Increase availability of translated palliative care information materials in multiple formats/media**

When we asked palliative care service respondents to our survey ‘What would improve service utilisation for CALD communities?’ the responses were predominantly related to requests for more translated material in different formats:

- “Information provided - verbally and not just in writing.”
- “More audio visual aids”
- “Multi-lingual information. Written and visual”
- “DVDs”

When asked ‘What other resources would be useful for your organisation to improve cultural competency?’ respondents to our survey of Victorian palliative care services indicated:

- Audio/visual material (e.g. DVD) with cases studies: “More audio visual aids” and “Tapes/videos/diverse brochures.”
- Availability of translated written material (without services having to produce translated materials themselves): “Time, funding and assistance to reproduce relevant and useful material in other languages.”

There is a strongly shared view among those that we interviewed that providing information in visual or audio format increases the chance of successfully conveying the message. This is particularly important for clients with low literacy levels and/ or during difficult times in their lives; below are selected quotes:

This is supported by our search of resources which identified examples of materials developed in-house, for example:
A language services toolkit developed by Palliative Care Goulburn Valley Primary Care Partnership identified opportunities for agencies to use best practice development in the provision of interpreting and translation services to enable better access to rural primary care services for people from diverse cultural and linguistic backgrounds.  

The Australian Multicultural Foundation developed a model for delivering health messages to newly arrived communities. An example of this was a campaign to increase dementia awareness through ethnic radio for newly arrived communities.

Centre for Culture Ethnicity and Health developed a health promotion DVD to ensure that the needs of migrant and refugee communities are addressed in state-wide responses to problem gambling.

Centre for Culture Ethnicity and Health have developed tip sheets on how to translate health promotion materials into different languages and review existing translated materials.

Test information within the community

Written materials are helpful for people who read and comprehend at the level at which the materials are written. Translating such materials into second languages with complete accuracy is difficult, especially to less-common languages. In all cases, written materials require review and confirmation by content and language experts.

For example, services can run focus groups to talk about palliative care and ask each community how best to communicate and promote it. Each community will have different needs and different communication models will be appropriate for each group.

Implement a strategy to monitor the effectiveness of each promotional activity/campaign

Due to limited funds available for the promotion of palliative care services, particularly strategies targeting CALD communities, it is important that all promotional activities and campaigns are evaluated for their impact.

In an interview with the Australian Multicultural Foundation (AMF), a recent campaign to raise awareness of dementia within ethno-specific communities was discussed. The campaign was largely conducted via SBS radio. To measure its effectiveness, the AMF monitored the number of enquiries they received. This type of monitoring requires limited funding. With greater funding, evaluations of awareness can be conducted with survey tools. The University of Wollongong developed such a tool that evaluates palliative care awareness within the community.

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36. Joint project into Promoting Partnerships in Peer-Led Self-Management of Chronic Disease; 2004
Section 5: Utilisation of palliative care services by CALD communities

This section presents evidence derived from the literature review, in-depth stakeholder interviews and the survey of palliative care services that provide insights into: a) the barriers to the utilisation of palliative care services by CALD communities and b) strategies to improve utilisation by CALD communities of palliative care services. It builds on the preceding sections relating to raising awareness, partnering with ethno-specific communities and developing workforce capacity to provide culturally responsive services.

**Barriers to utilisation of palliative care services**

*Family structure*

The literature identifies that many seniors from CALD backgrounds remain at home caring for their grandchildren or supporting the family. The ethnic aged were found to have lower incomes, a lower rate of home ownership, more restricted family networks, and greater likelihood of feeling isolated. However, a higher proportion was married and therefore had the support of a spouse. Older immigrants were also more likely to be dependent on government pensions. Marital status can be an important indicator of family resources and social wellbeing.

Living alone is much less prevalent for older persons from Asian and Southern European countries than for older persons from Western or European countries or Australian born older adults. There is not much difference in the proportion caring for someone who is old, ill or disabled between the older people from CALD countries, the Australian-born, and others from English speaking countries.

With a shift towards more palliative care services in the home, there is an opportunity to promote to those who prefer to receive care in the home.

*Attitudes to seeking or receiving outside help*

Some cultures are reluctant to seek help as they feel they are undeserving or prefer to not have outsiders in the home.

> “Until you actually ask a client questions, they won’t realise that they have cultural differences... [For example] Chinese people may not want to ask for help, but they may not realise that this is a cultural difference”
> — Palliative Care Service Provider

*Limited understanding or cultural incongruence*

There are number of palliative care services that members from CALD communities may avoid, for reasons such as lack of understanding of what these services are, how and when to access to them, or lack of congruence with their specific cultural, religious and spiritual beliefs (e.g. pain expression, family involvement, and other unique cultural differences).

In response to the survey question regarding which barriers were most significant in limiting the use of palliative care services by people from CALD communities, 48% of respondents identified ‘reluctance to consider palliative care for specific cultural reasons’.

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38 National Seniors Australia; Productive Ageing Centre (2011). The ageing experience of Australians from Migrant Backgrounds. p.25
Cultural differences may include a reluctance to seek help (as they may feel they do not deserve it) or preference to not have outsiders in the home. Potential palliative care clients may rely on family and friends who may not always be available or may provide them with (negatively) biased information (Migrant Information Centre, 2009).

- “Until you actually ask a client questions, they won’t realise that they have cultural differences” [for example] “Chinese people may not want to ask for help, but they may not realise that this is a cultural difference”

Survey respondents also indicated that people from CALD communities are most reluctant to utilise the following palliative care services: counselling, pastoral care, bereavement support, and psychology services (see Figure 3 below). By contrast, these are some of the highest priority to improve areas for carers and bereaved carers.  

These findings are also consistent with the views of those we interviewed. Reasons cited for the low take up of counselling services by the CALD community include the lack of availability/access to bi-lingual interpreters and a lower priority being accorded to this service compared with other palliative care domains, such as pain management.

**Lack of timely referrals to palliative care**

A lack of timely referrals to palliative care services by primary care practitioners was a view shared by all 28 interviewees in the palliative care sector. This is perceived as being more of a challenge when language and cultural barriers exist.

A tendency for the medical profession to want to be “curative” rather than improving quality of life was another common perception among the palliative care sector. Interviewees felt the following factors contribute to a lack of timely referrals by primary care practitioners:

- A lack of understanding about palliative care services;
- Not wanting to talk about death and dying;
- A feeling of ‘failure’ in their effort to prolong the life of their patient.

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Other barriers that affect the use of palliative care services include; considering palliative care for specific cultural reasons (47%), and reluctance to seek support of formal services (37%). The fourth largest barrier was found to be failure to make appropriate and timely referrals to palliative care by some health professionals (31%).

**Administrative requirements**

Administrative requirements for receiving services are too demanding. The amount of forms to fill out or the type of information requested may seem very intrusive. 

**Other Strategies to increase utilisation of palliative care by CALD communities**

**Increase awareness of palliative care among health care practitioners**

Primary care practitioners play a significant role in informing and educating patients, thereby enabling patients to make informed decisions that affect their health and treatment, including effective and timely referral pathways to palliative care. Increased utilisation of palliative services will require increased awareness of palliative care among the general community and health care professionals.

Cairns and Yates (2003) concluded that the growing demand for palliative care in Australia means health professionals are expected to provide palliative care as a core part of their practice. Training in the practice was a recent addition to undergraduate and post graduate medical and other healthcare curricula, and several initiatives are under way to promote palliative care principles and practice in health care training. In many of the specialised areas of medical and nursing practice, particularly: general practice, the oncological specialities, and pain medicine, encouraged their trainees to spend time working in palliative care services and/ or included examinable requirements for an understanding of palliative care and related medicines. The challenge is how to develop these skills in the face of multiple demands on their time.

Primary care practitioners need to be aware of an individual patient’s beliefs and practices of the community from which the patient belongs, as well as inquiring whether or not an individual patient adheres to these cultural beliefs. Attention to cultural difference will enable primary care practitioners to provide effective care or timely referral to palliative care.

CareSearch is an online resource of palliative care information and evidence. There is an education module on the site that provides information on a range of educational options relevant to palliative care.

**Improve communication between the patient and doctor**

In many cultures, it is expected that the family will be responsible for the care. However, despite the positive value ascribed by many to such involvement, extensive family involvement often arises from very negative situations. It is imperative that palliative care services provide culturally competent care and involves a better understanding of issues of collusion and its multiple manifestations across settings and cultures.
Collusion, which refers to any information (about the diagnosis, prognosis, and medical details about the person who is ill) being withheld or not shared among individuals involved, is especially common in palliative care settings. Determining the amount of information disclosed to all the involved parties is further complicated in CALD families, where strong beliefs about familial responsibility for decision making are likely to prevail. In traditional and developing societies, the family plays a significant role in each stage of healthcare giving - the screening, diagnosis, treatment, and follow-up. Thus, culturally sensitive care must weigh the costs and benefits of collusion, and determine how this interacts with personal and cultural beliefs.

Below are some comments from palliative care service providers that we interviewed:

- “It is a really difficult tightrope. I think most of the staff would say you are walking a fine line. If they are an un-well person and we need to be in there for symptom management, and the family are saying you must not discuss death and dying...you really need to work with the family. Most of us will say, ok, we will respect your thoughts and wishes. But if the patient asks us directly, we will not lie to them.”
  – Palliative Care Service Provider
- “They will either be over serviced, or underserviced” “some families can create a chaos because of their cultural differences, and we respond to that anxiety”
  – Palliative Care Service Provider

According to Kemp (2005), when working with families from other cultures, it is often necessary to explain how the health care system (including palliative care) works and the value of family involvement.

**Improve referral pathways to palliative care**

When asked to describe strategies to increase service utilisation of palliative care within CALD communities, our survey respondents identified timeliness of referrals as a key strategy:

- “Ensuring referrals are timely to enable face to face interpreters to be located”
- “Increase the ability of potential referrers to have adequate conversations around referral to palliative care”
- “Early referral of patients and carers so that relationships have time to develop and resources can be sourced to make communication and understanding better.”
- “Part of our strategy to improve access for families to paediatric palliative care and Very Special Kids is to network with service providers and develop relationships with paediatricians, social workers and other likely referral sources who interact with families.”

Whilst the literature review did not find any recent Australian studies examining the transition into palliative care, there was a recent examination in England. Secondary care professionals reported that discussions about adopting a palliative care approach to patient management were not often held with patients. Primary care professionals confirmed that patients were often discharged from hospital with “false hope” of cure because this information had not been conveyed. Key barriers to ensuring a smooth transition to palliative care include: difficulty of letting go in an acute hospital situation, professional hierarchies that limited the ability of junior medical and nursing staff to input into decisions of care, and poor communication.

Overall, further research needs to be designed to specifically target disease areas and processes of care to identify indicators for effective and timely referral to palliative care and such research needs to include CALD populations.

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Providing tools to assist healthcare practitioners manage transitions to palliative care and the communication of diagnoses will facilitate a timely and effective referral process.

Advance care planning

Many of the palliative care services that were interviewed noted that advance care planning is a relatively new concept to palliative care. Advance care planning has yet to be fully implemented and further consideration of how this might be done with CALD communities would be beneficial. Some quotations from the stakeholder interviews are as follows:

- “The whole concept of advance care planning needs to be focus tested. We are assuming that this concept will be adopted and embraced and actively apply by CALD.” Palliative Care Service Provider
- “[Advance care planning should] eventually be in different languages” Palliative Care Service Provider

The need for complementary models

While mainstream services appear to be the preferred model of community aged care service delivery, the literature indicates that these services are not currently able to meet all the needs of older CALD people. In addition, the literature offers abundant evidence to support the value and effectiveness of ethno-specific services for CALD older people, while at the same time emphasising the inability for these services alone to respond to the needs of all of Australia’s ethnic communities, and particularly smaller groups.

Review of the literature also highlighted that a critical factor is how the various models can best complement each other. Consequently, the prevailing wisdom indicates that it is not a question of an ‘either or’ approach. Both the published and unpublished literature indicates that the future of community aged care service delivery for people from CALD backgrounds lies in the coexistence of mainstream, multicultural and ethno-specific services working together and in partnership. In summary, there remains very little systematic, published evidence-based research that has as its focus the delivery of community aged care services to people from CALD backgrounds. The outcome of this review suggests the need for further research and investigation.

Additional strategies

Some additional strategies were identified from our stakeholder interviews and survey of Victorian palliative care services:

- Greater access to the Program of Experience in the Palliative Approach (PEPA) program – this program aims to improve the quality, availability and access to palliative care for people who are dying, and their families, by improving the skills and expertise of health practitioners and enhancing collaboration between service providers. PEPA offers:
  - Supervised clinical placements in specialist palliative care services (community and inpatient)
  - Integration of learning into practice
  - Post-placement support
  - Tailored workshops
- Having a palliative care advocate placed in a hospital setting to educate and mentor other practitioners.
- Maintaining relationships and networking via health conferences and forums to engage health practitioners.49

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49 Program of Experience in the Palliative Care Approach (PEPA), http://www.pepaeducation.com/
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