



Culturally safe by design:
The Palliative Support Project
of United Spanish Latin American Welfare Service,
Melbourne

Lucy Buchanan and Rose Ova,
Social Work Honours students, RMIT
on placement with Palliative Care Victoria

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Summary

Palliative care approaches recognise the importance of community involvement and support in terminal illness trajectories and end of life care. Among the Australian Spanish-speaking community, there is often limited knowledge of palliative care and end of life supports available. However, given Australia's ageing migrant populations, a focus on culturally and linguistically diverse palliative care support is gaining interest.

In 2019, United Spanish Latin American Welfare Centre (United) was funded by Palliative Care Victoria (PCV) to introduce a palliative approach to its existing aged care programs. The project was designed collaboratively by PCV and United, with PCV providing training resources and a palliative perspective. United contributed cultural expertise, training and management of project activities. The project aimed to extend capacity of existing volunteers to provide psychosocial palliative support to Spanish-speaking community members with a terminal/chronic illness.

The United palliative support project successfully raised community awareness about palliative care, upskilled a cohort of volunteers to support people with advanced illness and improved well-being and social connection for Spanish-speaking individuals with a life-limiting illness. This paper documents the United experience in implementing the Palliative Support Project.

Background

Palliative care is an approach which "improves the quality of the life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual" (WHO, 2020). Palliative care is concerned with helping people live and die well, and generally refers to a suite of specialist care services aiming to support every person to have a good death (Abel & Kellehear, 2016).

It is recognised that death and dying cannot be entirely the role of medicine or the hospitals and there is a move to place it back into the hands of the community with medical support (Guilbeau 2018, Abel & Kellehear, 2016).

Kellehear's framework of a compassionate community offers one such model of collaboration bringing together healthcare professionals, primary caregivers and civic society (family, friends, volunteers, local associations, etc) to support people and their families at the end of life (Abel et al, 2021).

Through the compassionate communities model, groups organise themselves to provide training and care support for people approaching end of life (Librado-Flores, et al. 2018). This model of community engagement becomes particularly relevant for those missing out on accessing specialist palliative care, such as people living in rural and remote areas, cultural, religious and gender diverse communities (Abel, 2021).

Why culturally appropriate palliative care?

Australia is a multicultural country with approximately 29.8% of the population born overseas (ABS, 2021). The last 70 years has seen 6.5 million people settle in Australia through planned migration. In 2017, 3 in 10 older Australians aged 65 and over were born overseas (AIHW, 2018).

Palliative care requirements increase with age. The increasingly older age profile in many migrant CALD communities in Australia suggests there is an urgent need for tailored palliative care responses to meet specific needs of the community.

Current research suggests that across CALD and non-CALD groups there is much similarity in understandings and experiences of palliative care (Bosma et al, 2010). However, some potential differences surrounding palliative care may be evident in values such as:

- (i) “the desire to carry burden collectively,
- (ii) resistance to explicit talk about death and dying within clinical encounters,
- (iii) desire to care for and to die at home and
- (iv) use of traditional medicines or healers as part of supportive care.” (Broom et al., 2018)

Palliative care in Spanish-speaking communities

Research on palliative care in Spanish-speaking (as in the English speaking) communities around the world indicates that community-led psychosocial support for terminally ill patients is still evolving. A key focus of specialist palliative care is delivering treatments to manage disease and prevent suffering (Gomez-Batiste, 2017). To deal with increasing incidence of chronic illness and identified needs in the ageing population, the palliative care sector developed a model of home-based palliative care which included social welfare and companionship. (Molina, 2013).

Kellehear’s model of compassionate communities was introduced in 2015 to several cities in Spain and Latin America through the All with You® (Todos Contigo® in Spanish) program. This program was designed to enable people who are living with advanced illness or facing end of life to receive support through an integrated model of clinical and social services. The model focuses on community awareness and training for volunteers who provide services through development of care networks with specialist services (Librada-Flores, 2018).

Cultural strengths and beliefs

The Spanish-speaking community in Melbourne includes migrants from Spain and Latin-America. Much of today’s Spain-born population comprises those who migrated to Australia in the 1960s as children or as adults (Cultural Atlas, 2021). Migrants from Latin America came in two waves in the 70s and 80s under the humanitarian program and those who arrived in the 90s as international students and family reunion programs (Del Rio, 2014).

Latin America is a ‘historically complex and heterogenous continent’ that generally refers to South America, Mexico, Central America, and the islands of the Caribbean (Cupples 2018, p. 2). The common heritage linking these countries was the Spanish and Portuguese colonisation from the 15th to 18th centuries and their subsequent independence from Spain and Portugal during the 19th century that has left lasting ‘cultural, political, social, economic, spiritual, and linguistic legacies’ (Cupples, 2018).

An American review on the integration of cultural values into palliative care found that Latin American patients identified five core values concerning end of life care:

1. *Familisimo* (family-centred socialisation with considerable connectedness and interdependence),
2. *Personalismo* (according to Falicov, when establishing relationships with professionals, Latin Americans require rapport building that includes warmth, informality, and regard),

3. *Respeto* (reveals the hierarchical structures that may exist in Latin-American communities),
4. *Confianza* (trust; regarding to when someone expresses his or her deeper feelings only to an inner circle of familiar confidants, and establishing relationships with reciprocal trust),
5. *Dignidad* (dignity; associated with worthiness and feeling valued)' (Adames in Zertuche-Maldonado et al, 2020 p.72)

Understanding and respecting cultural beliefs are critical to providing palliative care to patients of Spanish-speaking background, as culture shapes understanding and navigation of dying processes (Adames et al., 2014). Upholding cultural values may increase the likelihood of an individual having a good death and for end-of-life care to be culturally safe and sensitive.

In Australia, there is currently no available research on Spanish-speaking migrant experiences with palliative care.

This paper documents the approach and experience of the Palliative Support Project implemented by United Spanish Latin American Welfare Centre (2019-2021).

The paper was prepared by Lucy Buchanan and Rose Ova, Social Work Honours students from RMIT University on placement with PCV. The paper has been prepared in partnership with United.

Palliative Care Victoria

PCV is the peak body for palliative care and end of life care in the state. It was established in 1981 and is supported by the Victorian Government, palliative care organisations and individual members, other groups and funders.

The United Spanish Latin American Welfare Centre

United was founded in 1977 to respond to the settlement needs of refugees and migrants from Spain and Latin America. United supports Spanish-speaking individuals from 22 countries through a range of services, including an information and referral service, education and community development activities, support for international students and a range of aged care programs.

The United Palliative Support Project

Since 2017, United had partnered with PCV to train a bilingual educator and facilitate several community information sessions in palliative care. Late in 2018, United extended the community information to Seniors' groups in metro and rural Victoria.

In 2019, United and PCV collaborated on an initiative to introduce the palliative approach to its aged care services. This involved extending capacity of volunteers to provide psychosocial palliative support to community members with a life-limiting illness. PCV provided the funding, training resources and the palliative perspective. United contributed its cultural expertise, management and training capability.

Volunteer training and management

United adapted a training manual from PCV's Volunteer Training Resource, tailoring the information to their volunteer needs and translating it into Spanish. The Volunteer Coordinator also prepared a referral list of services available to Spanish speaking community members to assist volunteers provide relevant practical information.

PCV supported new project staff with information on online training courses in palliative care and an introduction to staff from the local palliative care service, Mercy Palliative Care.

The project was initially promoted at various meetings with local community groups, through an interview broadcast on community radio (SBS), by word of mouth and social media.

Six volunteers were recruited. A training session was organised for the volunteers which focused on needs at end-of-life, providing practical assistance and psychosocial support to clients living with a chronic illness or nearing end of life.

United matched five of the six trained volunteers to five clients who met the eligibility criteria of having a terminal/chronic illness. Volunteers met their clients through weekly visits initially and later maintained contact through phone and video calls. In one case, the volunteer accompanied the client to weekly medical appointments as there was no other family support.

Debrief sessions were provided to volunteers to talk about different issues they were facing when communicating with their client. Individual supervision for volunteers and monthly team meetings aimed to extend knowledge and skills.

Culturally responsive support

The United Volunteer Coordinator, Jackeline Quintana, reported that initially, she did not know much about palliative care as there were no similar services in her home country: 'I had to really research the topic well before the project was implemented.' Jackie also attended online courses on palliative care and a palliative care training at PCV.

Jackeline reported that among Australian-Spanish-speaking people, experiences of death and grief are diverse. 'Mexican culture celebrates death whilst, many Spanish speaking countries find the topic taboo.' The information sessions were duly modified. 'I had to deliver the palliative care information in a way that didn't discuss death and dying directly... I opted to frame the services available for exceptional circumstances or if someone has a chronic illness'. This approach allowed for a more receptive response from service-users.

One of the tasks of the project was to challenge the belief that you have to stay strong and appear happy when experiencing grief. Grief is normal and that is the narrative that Jackeline has been trying to promote throughout this project. 'I believe that it is important to make the change from suppressing your grief to allowing for space to grieve, it is possible to be both strong and sentimental'.

Some of the service-users do not have family in Australia and many of their friends have passed away. Cultural values of connectedness, dignity, respect and trust characterised relationships with clients. 'Feedback from clients has been great', says Jackeline. 'Many report that they no longer feel alone in this journey, the days feel shorter when they are with the volunteer. Others have reported that they do not feel (so much) pain when their volunteer is with them.'

'Many of the volunteers feel like it is their responsibility and duty to really be there for their clients,' said Jackeline, 'especially when they see their client's health decline'. The strong cultural value of supporting others in hard times was evident through this project and is undoubtedly a strength of the community.

Supporting people with dementia

One concern for Jackeline was the willingness of volunteers to support service-users with advanced dementia: 'One of the clients had stage four dementia and I was worried that I would not be able to link them in with someone. However, once volunteers were trained with the palliative care approach, they were happy to support the client as they had a better understanding of their roles and how their support could impact the client's life.

The COVID-19 lock-down prevented home visits which led to clients missing out on face-to-face social support. Letter writing, phone and video calls enabled contact. Some clients were reluctant to speak on the phone, but volunteers were encouraged and motivated to continue reaching out. Home visits re-commenced in December 2020.

Loneliness and isolation are a common experience amongst ageing communities. The Spanish speaking community drew on their cultural strengths of family-centered approach, supporting dignity, respect and building trust, to unite community members who might otherwise be alone in their illness and end of life journey.

The program was culturally safe by design, with all services provided in Spanish language and with consideration for individual need and sensitivities. By its nature, training individuals to provide palliative care support to other people within their community in need was found to be both empowering and highly beneficial by both the volunteers, clients, and the wider community.

Online forums for volunteers across projects

Two online forums for volunteers across the three PCV funded (Ethiopian, Serbian and Spanish-Speaking) palliative support projects were organised by the Serbian Community Association of Australia.

Volunteers and their managers from each project reflected on their experience and lessons learned through their work with seriously ill people. They shared stories and concerns. Many volunteers were determined to continue their visits regardless of the program funding ending. They agreed that the journey was slow at the start but by the end of it, everyone had gained experience and were better prepared to deal with various challenges. The volunteers reported great satisfaction in providing support. They noticed improvements in the general wellbeing of their clients after they commenced their visits.

Challenges were also discussed: one difficulty was communicating with clients with dementia. Volunteers reported dementia clients may not show interest in visits at times or recognise the volunteers.

The volunteer coordinators discussed how they supported the volunteers through regular debrief and supervision meetings.

The participants in the forum agreed that there is great need for similar projects in all CALD communities.

A volunteer experience

Paulina, a volunteer in the Palliative Support Project joined the program when she heard that aging people in her community needed more help.

“Here (in Australia) we are alone, without family”, she explained. “This is a beautiful country, but we don’t have our family around us.

“I have a client who has diabetes and she has to go to the hospital for dialysis, she has a lot of pain. Sometimes I go into the hospital with her.

“My mother is alone in my country (Chile) and she’s sick too and I believe if I am doing something for someone who is here maybe someone is going to do something for my mother. I have a lot of love in my heart to give. I like to serve. I prepare myself psychologically to get in touch with the clients who are in pain, who are sick.”

Paulina found the volunteer training offered by United supported her with the skills she needed to work with the complexity that can arise when providing psychosocial palliative support. “Since I have been at United, I am more prepared, I have more skills and I am learning how to improve contact with the client.”

Conclusion

The Palliative Support project drew on existing cultural strengths and values of the Spanish-speaking communities of Melbourne. The support reportedly improved well-being and social connectedness for a group of aging community members with a terminal/chronic illness. The project raised community understanding of palliative care and capacity of the ethno-specific organisation to provide psychosocial support in Spanish language to individuals and families in need.

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