

**Culturally safe and connected:
community-based palliative support in the
Serbian Community Association of Australia,
Melbourne**



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PalliativeCare
VICTORIA
Living, dying & grieving well

Summary

Palliative care approaches recognise the importance of community involvement and support in terminal illness trajectories and end of life care. Among Australia's ageing migrant populations, a focus on culturally and linguistically diverse palliative support is gaining interest. The Serbian Community Association of Australia (SCAA) is a community based not-for-profit organisation, offering health and well-being programs to the Serbian community such as aged care services, information, advocacy and social support.

Since 2017, SCAA has partnered with Palliative Care Victoria (PCV) to deliver community information sessions on palliative care. From January 2019 to June 2021, PCV provided funding and partnered with SCAA in developing a project to introduce the palliative approach into its aged care services. This involved community education and building community capacity to provide psychosocial palliative support to members of the community living with terminal and life-limiting illnesses. The program reported a positive impact on the lives of clients, enhanced social connectedness and improved well-being through supportive relationships with volunteers, carers and families. At the end of the project, the volunteers transitioned to ongoing aged care support programs run by SCAA.

Background

Since the 1960s, palliative care has focused on improving quality of life for people with a life limiting illness, providing comfort and supportive psychological, social and spiritual care at end of life (WHO, 2020). Palliative care approaches see 'death and dying is everyone's business' and the belief that every person should be supported to have a good death (Abel & Kellehear, 2016).

It is recognised that death and dying cannot be entirely the role of medicine or hospitals (Guilbeau 2018; Abel & Kellehear 2016) and that much of the care for the dying and bereaved is already happening in communities, by community-based health services (Abel et al. 2021). These programs offer social, psychological and spiritual support to vulnerable groups as part of regular service delivery.

Supporting civic groups to care for their dying and the bereaved is particularly relevant for those who are not able to access specialist palliative services (Abel, 2021).

Kellehear's framework of a compassionate community aims to promote palliative care socially in the life of the community by building capacity of people to care for those facing end-of-life situations and fostering caring groups (Librada-Flores, 2018). At the same time, there is acknowledgement that challenges still exist in reaching ethnic, racial, religious and sexual minorities (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, which correlates to a projected increase in the percentage of older immigrants from culturally and linguistically diverse backgrounds (CALD). In 2017, 3 in 10 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 suggests there is an urgent need for tailored palliative care responses to meet the specific needs of the community.

Current research suggests that across CALD and non-CALD groups there is much similarity in understanding 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)

Since the 70’s with the first arrivals of Serbian people into Australia, the community has grown and today 23,542 people of Serbian ancestry live in Victoria alone (Victorian Community Profiles 2016 Census). For many Serbians, care at end of life is traditionally provided by extended families and community. However, in the Australian context, ageing migrants may not have extended families or the systems of support available in their country of origin (Hiruy and Mwanri, 2014).

This paper documents the approach and experience of the Serbian Community Association of Australia in the implementation of the Empowering Serbian People in Need of Palliative Care project (2019-2021).

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

Palliative Care Victoria

Palliative Care Victoria 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.

Serbian Community Association of Australia

For 30 years, the SCAA has implemented a range of services designed to support Serbian-speaking families, carers and individuals living in Melbourne. Services included settlement support for newly arrived Serbian refugees in the 90s and social support programs for older Serbians, carers and families in recent years. SCAA also offers support groups for people living with dementia.

In 2017, the SCAA partnered with Palliative Care Victoria to train bilingual educators to provide community information sessions for members of the Serbian community in the south-east region. The success of the partnership encouraged PCV and SCAA to engage in a follow-up initiative: introduce a palliative approach and build capacity of the organisation to provide psychosocial support to community members living with a terminal/chronic illness. PCV provided the funds, training resources and palliative care perspective. SCAA developed a comprehensive training and supervision program in the palliative approach for its volunteers. Over the first year, SCAA established a palliative support program to meet needs of Serbian-speaking clients with terminal/chronic illness.

The SCAA Manager, Marina Celebic and Volunteer Coordinator, Biljana Trickovic played key roles in designing the project with PCV and continued to adapt project activities to the changing needs of a community during the COVID-19 pandemic.

Respecting cultural sensitivities

At first, two aspects around end of life needed to be addressed sensitively: taboos around speaking about death and honouring bereavement and mourning rituals.

Taboos around Death

Among the Serbian speaking population, death is often a taboo topic, 'if we don't see it, it's not there'. Death was not talked about. A further complication was that there is no translation for palliative care in the Serbian language. This resulted in individuals and families missing out on access to critical support, unaware of services available for people living with a terminal illness.

Mourning Rituals

Whatever the current traditions of the community, respect for individual and family beliefs was important. This meant accepting traditional mourning rituals and that these may differ from family to family. Rites of mourning are gradually shifting from expressions of grief and sadness to a celebration of life.

Starting up

In introducing the project and recruiting volunteers, Marina and Biljana had to promote the idea to the community by framing it in a positive way and speaking of death indirectly.

"In Serbia, the notion of palliative care is in its infancy and the responsibility for looking after terminally ill individuals is largely a matter for the family and the hospitals, with end-of-life care often understood in medical terms," said Marina.

During the first six months of operation, Marina and Biljana engaged in extensive promotion with community members and service providers to identify community members eligible for palliative support. The project was promoted at meetings with local community groups in the area such as the women's group in Dandenong and Serbian pensioner groups in Keysborough and Carrum Downs and four Aged Care Facilities. Through these meetings, the project reached over 200 community members. A large number of referrals were received. After assessing for eligibility, nine people met the criteria for palliative support.

The project staff utilised the Serbian media such as the SBS Radio Serbian Program, Serbian Voice newspaper and MIS TV to extend awareness of the palliative support program among Serbian-speaking people. Overall, SCAA estimated around 7000 people in Victoria and 25,000 people nationwide were reached through this campaign.

Building volunteer capacity for a palliative approach

The Project Manager prepared and translated a Training Manual in the Serbian language, adapted from the PCV Volunteer Training Manual. Then SCAA spread the word about the new project to community and the service providers in the south-east region of Melbourne using the Serbian media and social media. This resulted in several people expressing interest in becoming volunteers.

Marina and Biljana reported that the flexibility of the program and the training in Serbian language for volunteers was met with enthusiasm. They believed their resource was key to this, as the training manual translated into Serbian was carefully crafted to cultural considerations.

Seven volunteers were initially recruited to attend the first training sessions in June 2019. Each received a copy of the manual to assist in understanding their role in providing psychosocial support. Each volunteer was matched with a Serbian speaking client residing in a care facility.

Monthly skills training sessions and fortnightly individual/group supervision was provided by the Volunteer Coordinator to support the volunteer and assist problem-solving.

PCV supported the project staff with information on online training courses in palliative care and other training for ethnic aged care workers. SCAA invited a palliative health professional from the local palliative care service, Palliative Care South East to speak to the volunteers about their service.

Making a difference to the lives of people with terminal/chronic illness

Over the next few months, the volunteers noted positive changes in the clients, evidenced by smiles when they met with the volunteers and their delight when the volunteers would accompany them on walks, in singing or listening to music together. The volunteers reported that regular visits were the key in seeing improvements in the client's life, allowing a bond to develop, understanding and trust to be established. Marina and Biljana report that the volunteers felt they were making a change in the lives of others and in their own.

Clients reported benefit from being able to socialise and receive support in Serbian, their first language. One family member noted that their mother 'came alive' when her volunteer visited as they could speak and exchange stories in Serbian. Volunteer visits provided respite to carers as well.

Feedback from staff at the nursing homes related to the positive impressions made on the service and clients and noticeable improvements in mood and satisfaction with such visits.

The volunteers subsequently assisted SCAA to recruit more volunteers through their own social networks. A second round of training was implemented for provision of psychosocial palliative care support in Serbian language.

Over the two-year project period, 17 volunteers were recruited, providing support to 34 individuals with a life limiting illness and approximately 136 immediate family members including spouses and children of the person (indirect beneficiaries).

The Impact of COVID

The COVID-19 pandemic reduced the capacity of volunteers to visit clients in person. Face-to-face visits were replaced with telephone, video calls or the online forum. The Volunteer Coordinator, Biljana, provided supervision and ongoing training to the volunteers through WhatsApp, Viber and Skype. These telephone applications enabled the volunteers to maintain regular contact with the people they were visiting.

Despite the COVID-19 restrictions imposed during the lockdown in February 2021 and May-June 2021, the volunteers had regular contact with their manager and client, providing and receiving support successfully.

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 to be visited sometimes and forgot who the volunteers were.

“Since the Serbian community have a larger and older community, each volunteer might have 3 to 4 clients to see, which could sometimes be challenging in addition to the clients’ different health related issues”, reflected Ezana Getachew, Coordinator of the Ethiopian Palliative Support Project. “Our community does not have a large number of elders in aged care facilities, as most members are first-generation Australians. We will learn a lot from the Serbian experience to support our elders in future.”

The volunteer coordinators discussed how they manage grief with the volunteers. All the projects held regular debrief and supervision meetings with the volunteers to share experiences.

The participants in the forum agreed that there is great need for such programs.

The work continues...

As the project neared its end, the Volunteer Coordinator utilised supervision meetings to discuss transition planning individually with clients and volunteers. All the volunteers voted to continue in other aged care service programs run by the SCAA.

The SCAA hopes to be able to continue supporting Serbians to provide community palliative support into the future, though this would be reliant on securing funding.

“The success of the project strengthened connections with the community and various service providers. Our organisation gained knowledge and experience to enhance the quality of support services to members of the Serbian community”, said Marina. Volunteers from this project have continued to provide social support to recipients under different programs run by the SCAA.

Acknowledgements

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We also acknowledge that the views in this paper do not necessarily represent all those who participated in the project, limited as we were by time and the COVID-19 lockdown in Melbourne.

A final thank you to the team at Palliative Care Victoria where we are currently undertaking our final placement, for their assistance and support in preparation of this document.

The story of Zora*

Zora is 93 years old. She has been diagnosed with dementia.

Zora lives at home with her daughter, Nada, who works full time and is unable to be with her during the day. Nada heard about the SCAA program through the media campaign and asked whether the project could provide a volunteer to visit Zora or at least call her during the day. Nada informed that her mother has advanced dementia and has reverted to Serbian. She thought it would be great if her mum could have contact with someone who spoke Serbian.

Volunteer Mira, who recently came to Australia, is a registered nurse with many years of experience. She was matched with Zora. Due to COVID-19 restrictions in place, Nada was keen to have Mira call Zora over the phone rather than conduct face-to-face visits.

Mira was conscious of the difficulties in contacting Zora over the phone rather than in person. Despite her nervousness she made the first call to Zora and introduced herself. Nada was present during this call which unfortunately confused Zora. Nada remained on the first few calls and noticed that Zora was animated and lively after speaking to Mira in Serbian, so she asked Mira to continue calling her mum. Mira continued to make a weekly call to Zora.

Despite their regular contact, as a result of dementia, Zora would sometimes have a bad day and could not remember Mira. However, she was always ready to share her memories with Mira.

Nada reported how happy she was that her mum had someone to talk to in Serbian and commented that Zora's communication skills stopped declining noticeably.

As the palliative program came to an end, Zora was transitioned to the Community Visiting Scheme program and Mira maintains contact with her.

*Names have been changed to protect the identities of the volunteers and clients in the program.

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