Overcoming cultural taboos: Community palliative support in St Michael's Ethiopian Orthodox Church, Melbourne

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25/10/21

PalliativeCare VICTORIA
Living, dying & grieving well

Summary
Palliative care approaches recognise the importance of communal involvement and support in terminal illness trajectories and end of life care. Given Australia's ageing migrant populations, a focus on culturally and linguistically diverse palliative care support is gaining increasing attention.

In 2019, Palliative Care Victoria (PCV) partnered with Debre Genet Saint Michael Ethiopian Orthodox Tewahedo Church (St. Michael's Church) in the Western region of Melbourne to design a community palliative support program that would introduce the palliative approach to the community and develop capacity to provide psychosocial support to individuals with a life-limiting illness. PCV funded the project, providing training resources and a palliative perspective. St Michael's Church provided cultural expertise, management and community training and education services. A part-time Project Adviser and Coordinator were recruited to implement and coordinate activities of the project.

The project was successfully implemented, resulting in a palliative aware community and an enhanced capacity within the Church leadership to offer psychosocial and practical support to members with a terminal/chronic illness. When the project ended in June 2021, the volunteers and clients were transitioned to the Church welfare association and support continues.

Background
Palliative care focuses on helping people live and die well. It improves the quality of 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 approaches see 'death and dying is everyone's business'. Each community and family have their own meaning and understanding of death, dying and loss (Abel et al, 2021). While every person should be supported to have a good death, it is recognised that death and dying cannot be entirely the role of medicine or the hospitals. (Guilbeau, 2018; Abel & Kellehear, 2016).

As a person ages, illness and disability become common experiences, as does the giving and receiving of care. Families, relatives, church groups and health services assist those who are ill and dying to meet practical, emotional and spiritual needs. 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 gender 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

cultural and linguistically diverse backgrounds (CALD). 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 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 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)

There is currently a dearth of literature exploring CALD communities in Australia as they transition to palliative care. Hiruy and Mwanri (2014) describe a preference among CALD communities to seek spiritual care from community elders and religious leaders when unwell and nearing end of life, rather than seek support from Western medical systems or engage palliative care services.

It is usual within Ethiopian culture for care of persons with cancer or terminal illness to be the responsibility of the immediate family (Ayers, 2017). In Australia many aging migrants do not have these extended families and support systems therefore community support becomes even more important. In an increasingly diverse multicultural country, providing culturally safe and sensitive palliative care services must be a priority.

This paper documents the approach and experience of the Palliative Support Project implemented by St Michael's Church in 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 St Michael's Church project staff.

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.

St Michael's Ethiopian Orthodox Church

St. Michael's Church provides a range of moral, spiritual and educational services for members of the Ethiopian communities in the western suburbs of Melbourne. St Michael's is one of five Ethiopian Orthodox Churches in Melbourne which has over thousand members. St. Michael's Church provides spiritual services and other essential community services such as homework support for children to improve their numeracy and literacy skills (funded by the Victorian government), language, welfare and counselling services. In 2019, the church successfully lobbied the Victorian School of Languages and opened three Amharic classes at the Creekside College in Caroline Springs.

Cultural strengths and challenges

Role of the church

The Church is far more than a place for the community to receive spiritual guidance. It is a social hub, engages in education for all age groups and hosts events for the wider Ethiopian community on significant days. On these occasions, there may be up to 1500 men, women and children joining in traditional festive celebration. Some welfare programs are run by the Church in partnership with other organisations and these are promoted to members on social media and at services. 'Observing others receiving support, creates interest and questions which then promotes discussion', says Dr Belayneh.

A compassionate community

In Ethiopia, it is common for the community in any area to mobilise a collective response significant events or misfortunes of members. People contribute towards funeral costs, feast days, weddings, building a community centre, etc. When a member dies, friends, neighbours and relatives visit, bringing food with them, staying to mourn with the family for several days.

Illness and spirituality

There is a social expectation to keep one's illness private, speaking of illness or disease is considered a taboo topic. As a result, people will often suffer in silence to avoid disclosure. Serious illness in the family carries a stigma and there is a sense of shame around disclosure (Ayers, 2017). Many from the community do not reach out for help nor accept help when it is offered to them.

"People say that they are fine and do not need anything. They do not like speaking of illness in public," says Dr Belayneh. "I don't think it is really appropriate, there is help and help is free. It still remains a problem, but we continue to educate".

It is easy for those who are seriously ill, to get lost in the background, especially if they do not have family or friends to support them. "People with depression or dementia in the community are at high risk of missing out on support," added Mr Getachew.

Faith

For many Ethiopians of the older generation, spiritual intervention is the only support they are willing to accept. "Back in Ethiopia, spirituality is very important, some people would even walk 4-5km to get to a monastery, some would die during the journey," says Dr Belayneh. "People believe that they will be healed if they go to a spiritual place".

Health professionals in Australia believe the patient has a right to know how long they are expected to live but the community believe it is in the hands of God not professionals to determine. Such disclosures are not generally received well.

The Palliative Support Project

In 2018, an elder in St Michaels Church assisted Palliative Care Victoria (PCV) to facilitate 6 community information sessions for faith leaders of Eritrean, Ethiopian and South Sudanese cultural background. The following year, St Michael's Church expressed interest in continuing the work.

St Michael's Church and PCV developed a project to introduce the palliative approach to the Ethiopian community and build capacity to provide psychosocial support to individuals with a terminal illness and their families. Funding, training resources and palliative care perspective were provided by PCV. St Michaels contributed cultural expertise, training and management support. The Church nominated a Project Adviser, Dr Teferi Belayneh and a Project Coordinator,

Ezana Getachew, to implement project activities. The project would train Church volunteers to provide practical and psychosocial support to individuals with a life-limiting illness under supervision from the Coordinator.

PCV supported the new project staff with information on online training courses in palliative care, organised training attended by the volunteers and met with staff from the local palliative care service, Mercy Palliative Care for a briefing.

A Volunteer Training Manual prepared by the Serbian Palliative Support Project, was translated into Amharic and used as a basis for a tailored training program. The Coordinator recruited and trained five volunteers and matched them to eligible clients requiring support. Volunteers were supervised to provide home visits, accompanied clients to appointments and social events and linked clients to other services as required. The volunteers received ongoing training from the Coordinator to enhance support skills.

The volunteers took a group-care approach to visiting the clients, taking turns to accompany them on social outings, appointments, church events and walks. Some prepared traditional dishes to share with the clients who lived alone and had no family members in Australia.

"I work in an age care facility", said Rahel, a volunteer. "This project has helped me understand more about palliative care. I also gained knowledge from the training and workshops which helps my future career pathway. I am delighted to be part of this project advocating the cause to our community which is shy to open up and speak about their illnesses. I am glad to see we have made a significant impact in supporting and creating awareness in our community."

Impact of COVID-19

During COVID-19 lockdown, face-to-face visits were replaced by phone and video chats. At this time, the project staff promoted the palliative care and COVID-19 information to the wider community through community radio (SBS) interview, social media (Viber). While producing a Fact Sheet on Palliative Care in Amharic and Tigrinya languages, the Coordinator identified a number of health and aged care service employees in the community. The Coordinator organised an online information session in Amharic, facilitated by a palliative care nurse.

St Michael's staff and volunteers meet with health professionals at Mercy Palliative Care in Feb 2020

The Palliative Support Project continued to educate and inform the community about care options for those suffering serious illness. Conversations and announcements at church events and

services explained the importance of accessing both medical care and spiritual care and that no need one need suffer unnecessarily.

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 managed grief with the volunteers. All the projects held regular debrief and supervision meetings with the volunteers to share experiences.

Increased awareness in the community

In the last six months of the project, the Coordinator began to receive referrals from local and other Ethiopian Churches, requesting assistance. Although not everyone referred meets the eligibility criteria of the project, the Coordinator visits them all for an assessment and follows-up with referral to an appropriate service or ongoing support. However, the project staff were pleased that community members were overcoming their initial hesitancy to discuss terminal illness and seeking help.

"The palliative care project has been an eye-opener to many Ethiopians who usually are never part of such a scheme", said Dr Belayneh. "Through a continuous effort of information exchange, engagement, training sessions, and an immense effort from our volunteers, we achieved our goal. We see the patients benefiting from the support.

"It is usually taboo in our culture for a person to speak of illness, or to receive palliative care. This belief still needs a lot of work to get rid of. However, with our experience in this project, we noticed that it is possible to change people's mindset for the good so that anyone in need of the support can benefit."

Before the project ended, a meeting of the St Stephen's Association (church welfare group) was organised to discuss the closing of the project and plan for its continuity. The Association

members showed great interest and commitment to supporting the palliative support work. The members believed helping the needy or visiting the sick is part of their religious values and hoped to continue improving their volunteer work in this area.

Conclusion

Working within cultural and spiritual beliefs and traditions and in the language of the community has been critical to gain the trust of community members in need of psychosocial palliative support. New relationships were forged with health workers within the Ethiopian community, including a medical centre with several doctors of Ethiopian origin.

The success of the St Michael's Ethiopian Orthodox Palliative Support project owes much to the skill of the Project staff in advocating an approach to palliative care education that combines respect for spiritual beliefs and access to medical care. Practical support to navigate services and reconnect to the Church community was also a critical aspect of providing care to individuals with serious illness.

Acknowledgement

We acknowledge our appreciation to the Program Adviser, Dr Teferi Belayneh and Project Coordinator Ezana Getachew, from St. Michael's Church Palliative Support project for sharing their experiences of implementing this project and to the volunteer team at St Michael's Church without whose participation this project would not have succeeded.

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.

And 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.

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