End-of-Life Care

Death and dying is a sensitive and personal journey. The process of end-of-life care can raise unique cultural, linguistic and spiritual considerations. The cultural, linguistic and spiritual needs of older people approaching end-of-life care needs to be integrated into the end-of-life care process and planning.

Australia is one of the most culturally diverse countries in the world however end-of-life planning processes don't always meet the unique cultural needs for people from culturally and linguistically diverse backgrounds.

In order to deliver quality and inclusive end-of-life care to people from culturally and linguistically diverse backgrounds it is important to be responsive to and respect their culture, language, spiritual beliefs and traditions, as well as additional individual needs, choices and preferences they may have.

There are many key terms to be aware of in the field of death and dying however this practice guide will outline three key terms below – palliative care, end-of-life care and advance care.

Definitions

What is Palliative care?

Palliative care is medical treatment and support given to an individual when they are facing life-limiting illness. This service is designed to meet the clients' individual needs and is provided in-home, at a residential facility, at a hospital or hospice.

What is End-of-Life care?

End-of-life care is part of palliative care. It involves effective communication with the family or carers, supporting them in the decision making process and creating an individual plan that will respect their cultural and spiritual needs and choices. End-of-life care is designed to bring relief and comfort for the client which is provided by all the medical staff and carers by offering emotional and spiritual support as well as advice, information and referrals to appropriate services.

What is Advance care?

Advance care is a process of recording the individual's future medical and health care plan in case in future they become unable or incapacitated to make important life decisions.

Key considerations

- Applying culturally appropriate end of life care practices enables people to have a safe and comfortable experience and can prevent distress for the person and their families and carers.

- In order to have culturally appropriate end-of-life care it is important to establish networks of trust with people from culturally and linguistically diverse backgrounds, their families, carers and advocates, the palliative care providers, primary doctors and specialists as well as the aged care providers and community cultural and faith leaders that the person trusts.

- Culturally appropriate end-of-life care training and resources are important in equipping aged care staff to engage effectively and sensitively with culturally and linguistically diverse people and communities.

- People from culturally and linguistically diverse backgrounds may have different approaches to openly discussing some medical and cultural issues. Consideration may be required to support their language needs such as finding a suitable interpreter and/or translator who can relay the medical information in a discreet and accurate manner.

- Understanding cultural issues is important to maintain the person's independence and dignity in regards to decision making, acceptance and utilisation of an advance care plan. Some topics which have cultural variations include practices and rituals around caring for the deceased person, telling the person about a life-threatening illness or disease, organ donation, will development and funeral arrangements, beliefs about the afterlife and approaches to grief and loss

Case study

Ethnic Communities' Council of Victoria (ECCV) advance care planning report

ECCV developed a report on advance care planning in collaboration with the Australian Filipino Community Services and the Macedonian Community Welfare Association in order to recommend future engagement with the Macedonian and Filipino cultural groups regarding advance care planning.

The project aimed to increase awareness of advance care planning for culturally and linguistically diverse (CALD) communities. The outcomes of the project included the community's recommendations to better engage and understand advance care planning. ECCV also designed a CALD advance care service model in response to consultations with these two communities.

The consultations revealed that that people from these communities had no knowledge of what advance care means nor what's involved.

For the Filipino community thinking about death and illness was considered "bad luck" and even discussing it could be "bad luck". The Filipino community was unfamiliar with the bureaucratic systems and processes and advance care planning was not usually discussed amongst family members.

Participants expressed that they wish to learn about advance care and planning for end-of-life care however in their culture it was deeply embedded that only family members look after for whoever in the family is either ill or passing away.

As the report explained, migrant communities in Australia usually give all the attention and importance to the family relationships and prioritise family members as carers. If there is an issue or an accident it remained in the family. For the Filipino community it was seen as wrong to talk about it outside the family. If someone interferes from the outside it was perceived as potentially causing problems and conflicts within the family.

In one of the cases that were reported, a Filipino woman had problems deciding whether to turn off her husband's life support and the hospital wouldn't allow her to see him or bury him. She believed that if his wishes were written down, she would have to respect his wishes instead of having to make the difficult decision to cut off his life support.

Other cases reported included mixed marriages where the women were much younger than the husbands and after the husband passes away they are left homeless, with no assets because everything was left to the kids. If this was planned there may have been opportunities to discuss assets in the will.

After these findings, participants in the community reference groups had suggested to create promotional material to introduce advance care planning in Filipino and promoted to the Filipino community.

Ethnic Communities' Council of Victoria (ECCV) advance care planning report (continued)

The report also mentioned the needs of the Macedonian community in Victoria. It stated that the Macedonian Community Welfare Association (MCWA) was interested in participating in this project and helped raise awareness and knowledge about advance care planning.

It is reported that the Macedonian community specifically seniors has little knowledge about advance care planning.

It is reported that Macedonians also relied on the extended family for support and care for older people and they were hesitant to ask for assistance elsewhere. Macedonian community members consulted with preferred to be informed of the person's diagnosis after which they decide if they would tell that person of the illness or not. It was often customary for the eldest son to tell his parents of the diagnosis, if one of them is gravely ill. It is said that older Macedonians have the expectations that the children will look after them when they grow old or become ill.

As the reports states, religion is also a big part of the Macedonian community. Church groups and networks was said to be particularly important to the older generations and have influence in the decision making process for older generations.

The Macedonian Community Welfare Association (MCWA) had suggested there should be training prepared to provide advance care planning support directed to the Macedonian community.

Additionally, this ECCV report recommended a 5 steps approach to increase awareness of advance care planning in CALD communities. Those are: Research and Data, Partnership and Consultation, Cultural Considerations, Key Communication Messages, Communications Framework.

Useful resources

Bridging Cultures

Cultural aspects of palliative care

Culturally Responsive Care – Communication

End-of-life care – My AgedCare

End-of-life and palliative care explained

Palliative care for culturally and linguistically diverse communities

Palliative Care Victoria – Other Language Resources

Providing Care and Comfort at the End of Life

LAST UPDATED: MARCH 2023

www.culturaldiversity.com.au