



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Diversity Dialogues

Summary and Recommendations

Topic

Difficult conversations: Talking about Advance Care Planning (ACP) with people from culturally and linguistically diverse backgrounds

Summary

On the Friday April 20th this forum was held to coincide with National Advanced Care Planning Week. Thanks go to Kim Greeve and Ruth Lopez from the Department of Health for agreeing to collaborate and for their help and support along the way.

Many thanks and much appreciation go to the panel members who gave so willingly of their time and knowledge. Without them the forum could not have succeeded. They were:

- Elizabeth Lang CEO Diversity Focus
- Bobby Mwakichako Richmond Wellbeing
- Abid Hussain Health Consumers' Council
- Kim Greeve Dept of Health

The purpose of this Diversity Dialogues forum was to assist those who utilise Advanced Care Plans in their work. The aim was to develop knowledge and understanding about working cross culturally with the objectives of encouraging and supporting people to work effectively with a culturally diverse range of clients and their families.

Thirty people attended the forum and engaged well with the panel members and in making recommendations for change. Some of the things we learnt included:

- Many people from South Sudan don't talk about death and are not comfortable to do so. Dying is something that is believed to be in God's hands and talking about it may incur negative things
- Start with the family regarding how to have the conversation with the unwell family member rather than conversing with that person first
- Be guided by the family
- Explain the concept of Advanced Care Planning (ACP)
- A culturally appropriate way to start this kind of difficult conversation is by having informal conversations with communities well in advance so people can go away and consider what has been said
- Try to keep staff who are providing information about ACP in the same age range as the patient. Older people may not consider a young person to be appropriate in this context. They are seen to be lacking in experience, including life experience
- It can be useful to bring religious leaders to help with the discussions as well as family members

In every instance panel members stressed the importance of including family in any discussion rather than addressing only the patient.

After the panel had spoken a Q&A session was held, this was lively and very engaging. Some audience members contributed from their cultural and experiential perspectives, adding value to the forum, while Kim was able to provide a wealth of information about the ACP. He also spoke about the development of ACP information in languages other than English (LOTE) and in spoken form i.e. video clips to provide a greater spread of information and support equity.

Recommendations

A vital component of Diversity Dialogues forums are the recommendations. These are intended to assist in improving delivery and increasing access and equity by informing providers and others involved in health service delivery and design including policy and procedure.

Recommendations from this forum were:

- People who attended this forum to take ACP brochures and printed matter away and comment/provide feedback to the Dept of Health and/or Kim Greeve
- A patient's ACP record to be placed in front of their file, or, if the patient is at home, keep it in a plastic bag or container on the fridge where carers know where to find it
- Greater community education is needed e.g. on topics such as dementia, ACP, this needs to be provided by the Dept of Health
- Take out the word 'patient' for community discussions and conversations, address people fully, personalise the information
- ACP needs to be taken out to communities so they can be educated on this, is this happening at a national level?
- Keep the information simple, avoid complex language
- Talk in terms of principles, values and dignity rather than 'planning'
- Ask communities what they want to call ACP – make it relevant to them
- Providers and departments need to develop community engagement strategies to improve knowledge sharing and distribution
- Providers and departments need to be open to community ideas
- Ensure interpreters are used as necessary

Evaluations

These indicated that 80% of attendees believed they had increased their knowledge and understanding in the area and also their ability to develop strategies that support equity in health care provision/services.

Responses regarding what people saw as the most interesting part of the forum were:

- Panelist presentations
- Listening to the guest speakers - excellent
- The diverse panel
- The Q&A session
- The general conversation - appreciated the willingness to share & build on suggestions
- The clarity of the panel members presentations - especially the emphasis on community education and adjusting Western language models
- Hearing from the panel, their perspectives and their lived experience from cultural perspectives
- Presenters' stories and Q&A
- Q&A

- The individual speakers on the panel and the Q&A session
- The Q&A - a lot of useful information about the different cultural backgrounds
- The panel and the Q&A
- Panel members, particularly Elizabeth
- Working with diversity in community sector contracts
- Panel members' experiences
- Information and education on cultural diversity and strategies to be used to promote ACP
- Cultural beliefs around end of life
- I enjoyed learning about other cultures and the implications of ACP in their community/culture

In response to the question "What will you do differently after this forum?" people wrote:

- Be more aware of how to work with family members to gain understanding about how to initiate discussions
- Talk about the lack of health literacy
- Take specific care on how to deliver difficult conversations
- More deliberately ask questions/permissions/protocols for various cultures
- Look more completely into my own advance care plan
- Look at engaging family in care planning when necessary
- This forum was interesting
- Talk to my community about ACP
- Listen to the elderly in a friendship group at the Lutheran church in Northbridge. These people are post WW2 former refugees.
- Have more compassionate conversations and try to relate to all
- Try to set up an end of life issues forum - but title it more compassionately (in our church community)
- Try to incorporate into my training for HCWs
- Ensure a cultural approach is sought before engaging in difficult conversations
- Think differently about the way I approach topics with CALD communities

Thank you again to panel members for your contribution on the day. You can see from the evaluation material that you really do make a difference and that your input is invaluable in supporting equity in health care delivery and provision.