

EVALUATION REPORT COURAGEOUS CONVERSATIONS WORKSHOP PROJECT

A joint project by

**Multicultural Communities Council of South
Australia & Palliative Care South Australia**



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*For priority population projects:
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Executive Summary

This report provides an evaluation of the *Courageous Conversations with CALD Communities* project developed by the Multicultural Communities Council of SA (MCCSA) and Palliative Care SA (PCSA), funded by The Department of Health and Wellbeing, SA Government, through the *Palliative Care 2020 Grants Program*.

Project Objectives

- to demystify palliative care and Advance Care Directives, and promote meaningful conversations about death, dying, and planning for end-of-life care within five targeted CALD communities
- to promote and facilitate the delivery of culturally appropriate information about palliative care and Advance Care Directive to communities via community-identified and endorsed mechanisms
- to foster increased connections between PCSA, MCCSA and CALD communities and community members interested in or concerned about palliative care.

Project Methods

The project used a Knowledge, Attitudes, Practice (KAP) approach to structure and evaluate a series of activities within target communities. Project evaluation was independently designed and conducted.

Stage 1: Sept 2020.

a) Fifteen leaders/facilitators from Chinese, Croatian, Greek, Hispanic, and Ukrainian communities attended a two-part, 5-hour *Multicultural Communities Courageous Conversation ‘Train-the-trainer’ Workshop* (led by PCSA) to equip them with the skills, resources, and information needed to lead activities and conversations within their communities (see [Appendix A](#));

b) a 29-item KAP survey was designed and administered to communities to compare pre- and post-intervention KAP (see [Appendix B](#)).

Stage 2: Oct 2020-Feb 2021.

Community leaders/facilitators disseminated the information gained in Stage 1 to their community via *Courageous Conversation Community (CCC)* forums. This included provision of information and strategies to promote courageous conversations.

Further activities were targeted to meet community needs, both in the materials provided and the means of communication (See [Appendix C](#)).

Stage 3: Assessment of KAP following project activities

a) Jan 2021. The KAP survey was re-administered to each community and results statistically analysed to compare community KAP pre- and post-intervention;

b) March 2021. Five community focus groups (total: 48 participants) were designed and facilitated by the evaluator to elicit community views about project activities and address the stated project objectives.

Groups were audio-recorded to enable review and qualitative analysis.

Project Results

All objectives were met. Supported by MCCSA and PCSA, community leaders’ awareness of available and/or preferred means of communication within their community enabled them to create and disseminate resources that were practically and culturally accessible.

Survey responses indicated that, post-intervention, there were meaningful increases in the level of community awareness of and discussions regarding death and Advance Care Directives, as well as regarding the provision of palliative care services.

Focus group discussions with members of each community confirmed that

- the project was successful in increasing their awareness of the value of discussions about death, dying, ACDs, and planning for end-of-life care
- although challenges remained, conversations about death and dying were important and useful, and, resources were available to help make them easier
- further efforts and activities were required to sustain and build upon communities’ increased awareness of and willingness to engage with these difficult concepts, and that without these, people were unlikely to convert awareness to action (i.e., to create an Advance Care Directive).

*Sometimes I have things don't want to say to anyone, but I can put in the ACD, like a special song I want and to go to the people who love me – I can write that down and put it in.
So the main point is
I can make it how I want to be.*

Finally, the success of the project relied, to a significant degree, on the trust and goodwill inherent in the extensive pre-existing relationships and network between the individuals and organisations involved. In this MCCSA played a pivotal role in introducing and supporting communication and interactions, acting as a bridge between PCSA and the CALD community-based organisations.

The language is a problem. ... the [What Matters Most] cards [with both languages on] really helps us, even in English because I need to know the terminology in English.

Even if you give us the ACD form, if someone doesn't explain, really explain in [language], what it is all about, we just cannot follow. I can talk in English, I can understand when I say it to you, but not always read or write. I need help and we'll do it together.

Project Recommendations

Based on increased targeted CALD communities' awareness of, and discussions regarding death and dying, palliative care services, and Advance Care Directives, recommendations are

1. that the project model continue to be developed and adapted within targeted communities.
2. that this model be rolled out to other CALD communities.

To continue to increase community awareness, future activities should include

- a. close collaboration with community leaders to ensure that all discussions and materials, as well as the timing and format of delivery meet community cultural needs and interests, whilst maintaining momentum and building on previous knowledge and/or activities.
- b. development of culturally based case studies or stories that feature the provision of palliative care that met individual, family, and cultural needs, and the making and benefits of Advance Care Directives, in order to increase familiarity and relevance.

- c. development of culturally endorsed resources in the language of each CALD community using
 - i. alternative modes of communication, as recommended by community leaders, that will be accessible to different groups—for example, visual or audio resources; and,
 - ii. idiomatic / lay language tailored to the preferences and literacy level of each community.
3. that trusted community leaders are identified and fully supported now and in the future to effectively and safely facilitate Courageous Conversations within their community. This may include
 - a. ensuring adequate (i.e., additional) time for community forums, especially where translation is needed, to enable more in-depth sharing of experiences and thought
 - b. providing additional information for leaders and communities about where and how they can access emotional support if required.
 - c. ongoing education and 'short refreshers' to reiterate and reinforce key messages within communities and ensure effective dissemination.
4. that the outcomes of community-led activities continue to be monitored and evaluated according to the extent to which they meet community needs.

We have a community network ... so we can and do piggy-back onto other things because we have a network we can use.

We do need the funding to help us to spread any message. We need support because we are volunteering.

And, we need to build on this momentum, though we need not to overload. So do a burst and break, then a burst. We know how to do that because of our networks, we can coordinate because we know our community.

It's culture culture culture. Palliative care is not just about end-of-life and death; we need to change to the belief that it is helping with long-term goals and you.

Summary Evaluation of Project Stages

Stage 1: Train-the-trainer workshop with Community Leaders

Fifteen participants from 5 ethnic communities (Chinese, Croatian, Greek, Hispanic, and Ukrainian) identified as leaders within their community and/or as willing to facilitate community conversations regarding death, dying, and planning for the end of life attended. Workshop sessions were facilitated by Mark Waters (PCSA) and included didactic sharing of information and strategies to promote courageous conversations alternating with small and large group exercises (see [Appendix D](#)).

Presentation of materials and large group discussion were in English, but small group discussions were typically in the language of each ethnic group, facilitated by use of card deck called *What Matters Most Cards* from Palliative Care Australia; these were translated into the language of each ethnic group (excepting Ukrainian participants, who used an English-language version; at their request, the community now has cards translated into Ukrainian (see [below](#))).

Evaluation of the workshop (led by a knowledgeable and approachable facilitator) indicated that this was experienced and endorsed by participants as a culturally safe and appropriate way to broach discussions about death and dying within their community (see [Appendix E](#)).

The availability of language-based resources was clearly important, as participants consistently valued the *What Matters Most* cards in written feedback, and their use prompted engagement and discussion within the group, often, independent of the facilitator.

Participants indicated that their own knowledge regarding palliative care, Advance Care Planning, and ACDs had increased, and that they were more aware of where to access resources regarding these.

However, although the workshop activities served to increase their own levels of comfort in discussing death and dying, the amount of information provided may have been in excess of what could be readily integrated, especially for those with relatively little experience in end-of-life matters.

Similarly, despite high levels of confidence in their knowledge obtained during the workshop, participants reported lower levels of confidence about their ability to run similar workshops within their specific communities.

These limitations indicated that ongoing support from MCCSA and PCSA was essential to ensure that workshop attendees were able to effectively and safely facilitate

project activities within their communities, particularly where this involved face-to-face sharing of information and discussions.

Stage 2: Community forums and associated activities

Following delivery of Stage 1, leaders/facilitators within each community undertook to disseminate the provided information within their own community through a *Courageous Conversation Community* (CCC) forum. Two Chinese language forums (Mandarin and Cantonese) were held, on advice from community (see [below](#)).

Given variation within the communities regarding available and/or preferred means of communication, the mode of delivery was tailored to meet specific community needs and/or preferences, sometimes scheduled during a regular meeting of community members (see [Appendix C](#)).

Following each CCC forum, a series of questions regarding the nature of community activities and outcomes were asked of the group with translation as needed (see [below](#)).

All reported that the information provided during the CCC forums was clear, helpful, and that they felt better informed about advance care directives. There was less agreement that attendees felt confident to complete the Advance Care Directive (ACD) form, specifically because forms must be completed in English. In addition, although agreeing about the value of the information provided, feedback was mixed regarding participants' views on extent to which they felt better able to have conversations about death and dying with family or others. This suggested that additional support was needed to ensure initiation and successful conduct of such conversations. Many participants sought out such support from MCCSA and PCSA as they subsequently designed and delivered information via other means to their communities. Activities included:

- discussion during other community forums
- radio talk-back broadcasts
- podcasts in language via ethnic radio
- specialised webpages
- articles in community newsletters
- posters, flyers, and other promotion
- distribution of Palliative Care packs to eligible elders

Led by facilitators/leaders who had attended the initial workshops, each community demonstrated enthusiasm and commitment in considering how to best tailor and adapt the information provided through a series of tailored activities to increase awareness of ACDs and palliative care, as well as increase community familiarity and ease of

engagement with conversations regarding death and dying (see [Appendix C](#)). Both MCCSA and PCSA facilitated this, providing resourcing and personnel time to support community activities.

This outcome was significantly reliant on the trust and goodwill inherent in the extensive existing relationships and network between individuals and organisations involved. MCCSA played a pivotal role in introducing and supporting communication and interactions, being a bridge between PCSA and the CALD community-based organisations.

Stage 3: Assessment of changes in community KAP following project activities

A survey was circulated to and within each community before (Sept 2020) and after (Jan 2021) project activities. The survey included 29 multiple choice, closed, and open-ended questions designed to assess community Knowledge, Attitudes, and Practices (KAP) regarding Advance Care Directives (ACDs), Palliative Care, and talking about Death and Dying. Community, gender, and age range were collected (see [Appendix B](#)). Pre- and post-intervention results were compared. See further detail [below](#).

Five community focus groups were conducted in March 2021. These were designed and facilitated by the evaluator, with questions focused on the stated objectives for the overall project. Groups were conducted at a time and place nominated by each community. Forty-eight participants provided signed informed consent to audio-record each discussion for review and analysis. See further detail [below](#).

Survey analysis (see [below](#)) indicated the following changes in respondent knowledge, awareness, and practices:

- *accurate understanding of palliative care*: Pre-intervention, 46.5% increasing to 73.3% post-intervention
- *awareness of palliative care services*: Pre-intervention, 64.6% increasing to 84.9% post-intervention
- *belief that a lack of knowledge about palliative care is a barrier to seeking care*: Pre-intervention, 53.5% decreasing to 26.7% post-intervention
- *knowledge of ACDs*: Pre-intervention, 45.5% increasing to 73.3% post-intervention
- *completion of an ACD*: Pre-intervention, 12.1% increasing to 23.3% post-intervention
- *had discussed thoughts of death or dying with others*: Pre-intervention, 67.7% increasing to 75.6% post-intervention
- *would seek specialist support to care for someone who was terminally ill*: Pre-intervention 73.3%, increasing to 88.5% post-intervention.

Analysis of focus groups (see [below](#)) indicated that, whilst there was some variation across targeted CALD communities, overall participants considered that

- the project was successful in increasing their awareness of the value of discussions about death, dying, ACDs, and planning for end-of-life care
- although challenges remained, conversations about death and dying were important and useful, and, resources were available to help make them easier
- palliative care was the most sensitive topic to raise within communities (being culturally unfamiliar and as implying impending death), requiring high levels of personal and cultural familiarity to do so, and a high degree of interpersonal trust
- further efforts and activities were required to sustain and build upon communities' increased awareness of and willingness to engage with these difficult concepts, and that without these, people were unlikely to convert awareness to action (i.e., to create an Advance Care Directive).

Other views commonly expressed included

- the importance of ensuring that the form, nature, and/or timing of information circulated was tailored to meet community characteristics.
- recognition that additional effort was required to reach particular sectors of each community that were more difficult to reach than others
- some concern about reliance on a small number (i.e., in some, only one person) of trusted individuals to lead or be a resource/contact person for information about these sensitive topics.

ACDs were commonly understood to be relevant to older persons (typically parents) approaching the end-of-life.

Perceived benefits to completion of ACDs were to

- enable individuals to state what was culturally, religiously, and personally important to them, as well as what they did not want for future medical care;
- minimise confusion, disagreement, and distress amongst family; and
- avoid wasting hospital or medical resources.

Perceived barriers to completion of ACDs included

- personal or cultural beliefs that the topic was confronting
- perceived lack of relevance (including that cultural traditions or family knowledge would guide care);
- practical impediments such as

- limited access to culturally accessible and/or appropriate resources,
- the complexities or time involved in completing the ACD

Project Recommendations

This KAP-based project constitutes a cost-efficient and feasible model to promote increased awareness of palliative care services, advance care planning, and Advance Care Directives, as well as increased familiarity with and willingness to engage in conversations about death and dying, within CALD communities. Actively engaging with communities throughout the life of the project, it serves as a ‘proof of concept’ to inform future efforts to empower these and other CALD communities (and individuals within these) to explore and share views regarding death and dying, and individual preferences for care at the end of life.

Critical in achieving these positive outcomes is sustained consultation and communication with individuals within communities willing to work with MCCSA and PCSA to:

- increase their own levels of knowledge and familiarity with these culturally sensitive topics
- tailor information provided to meet the specific needs and interests of their communities
- act as a resource within communities, not only to provide information, but also to refer and/or direct community members to available services.

As noted, the success of the project in meeting objectives rests on the trust and goodwill inherent in the extensive existing relationships and network between the individuals and organisations involved. In this MCCSA played a pivotal role in introducing and supporting communication and interactions, acting as a bridge between PCSA and the CALD community-based organisations.

Based on this evaluation, documenting meaningful and consistent improvements in the targeted CALD communities’ awareness of, and discussions regarding death and dying, palliative care services, and Advance Care Directives, recommendations are

1. that the project model continue to be developed and adapted within targeted communities.
2. that this model be rolled out to other CALD communities.

To continue to increase community awareness, future activities should include

- a. close collaboration with community leaders to ensure that all discussions and materials, as well as the timing and format of delivery meet community cultural needs and interests whilst maintaining momentum and building on previous knowledge and/or activities.
- b. development of culturally based case studies or stories that feature the provision of palliative care that met individual, family, and cultural needs, and the making and benefits of Advance Care Directives, in order to increase familiarity and relevance.
- c. development of culturally endorsed resources in the language of each CALD community using
 - iii. idiomatic / lay language tailored to the preferences and literacy level of each community; and,
 - iv. alternative modes of communication, as recommended by community leaders, that will be accessible to different groups—for example, visual or audio resources.
3. that trusted community leaders are identified and fully supported to effectively and safely facilitate Courageous Conversations within their community. This may include
 - a. ensuring adequate (i.e., additional) time for community forums, especially where translation is needed, to enable more in-depth sharing of experiences and thoughts
 - b. providing additional information for leaders and communities about where and how they can access emotional support if required
 - c. minimising the extent to which such duties rest on the shoulders of a few individuals, perhaps through active identification and recruitment of ‘leaders’ from different social and age demographics.
 - d. ongoing education and ‘short refreshers’ to reiterate and reinforce key messages within communities and ensure effective dissemination.
4. that the outcomes of community-led activities continue to be monitored and evaluated to determine to the extent to which they meet community needs.

Detailed Evaluation of Project Stages

Stage 1: Train the Trainer Workshop

This following is an evaluation of a 5-hour *Multicultural Communities Courageous Conversation Workshop* held at the Multicultural Communities Council of SA (MCCSA) premises in central Adelaide, on 1st September 2020. Mark Waters, Executive Director of Palliative Care SA (PCSA), prepared the content and activities (see [Appendix A](#)), with the workshop material and format reviewed by Helena Kyriazopoulos and Associate Professor Jaklin Elliott (JE: University of Adelaide / project evaluator). Based on the *Knowledge-Attitudes-Practice* (KAP) framework, the workshop had three aims:

1. to provide attendees with information and resources that would enable them to feel confident that they would be able to run similar workshops within their specific communities
2. that attendees' facilitation of such workshops within their communities would increase
 - a. knowledge and awareness within their community about that conversations about death and dying were possible and beneficial, thus increasing the frequency of such conversations
 - b. community awareness about palliative care and advance care planning
 - c. rates of completion of Advance Care Directives
3. to demonstrate that this training model was culturally acceptable and appropriate, and identify areas where further resourcing and assistance might be required.

A total of 15 participants from 5 ethnic communities (Chinese, Croatian, Greek, Spanish-speaking/Latino, and Ukrainian) attended (see Participant Demographics below). Participants sat with others in their community, and were identified as leaders within their community and/or as willing to work with and within their community to promote and increase the frequency of community conversations regarding death, dying, and planning for the end of life.

PARTICIPANT DEMOGRAPHICS (N = 15)*

Nationality	n	Gender	n	Age Ranges	n	Experience of providing support at the end of life**	n
Greek	3	Female	12	25-34	2	As family member	7
Ukrainian	3	Male	3	35-44	3	In community role	4
Spanish/Latin	3			45-54	2	As a friend	2
Croatian	3			55-64	6	None	4
Chinese	3			65-74	1		

Role within the community#	n
Priest	1
Community (care) worker	5
Community member/volunteer	3
Senior organisational leader#	3
Community leader	2
Placement student	1

* 5 participants attended; 14 forms submitted; one person left early due to pre-existing commitments, therefore N = 14 for Age Range, Experience of providing support at the end of life, and Role within the community

** 17 responses provided due to dual roles of some individuals

15 responses provided due to dual roles of one individual

includes CEO, Home care coordinator, Service Manager

Given the small numbers and specificity of the communities involved and to respect the privacy of individuals, demographic details have been collated into categories, rather than summarised for each individual. Participant details are included to provide context regarding the feedback.

Workshop Structure and Purpose

The workshop had three sessions with the purpose of each shared with participants (see Appendices A & D). Each session included specific content and associated activities, being a mixture of didactic sharing of information, alternating with small and large group exercises. A key feature of the materials shared were a pack of cards called *What Matters Most Cards* (typically referred to as 'cards' in feedback) from Palliative Care Australia; these were translated into the language of each ethnic group except for the Ukrainian community, who worked with an English-language version.

Session 1: Talking about dying

Purpose: -

- To Start a conversation about death and dying
- To identify cultural enablers and barriers to holding such conversations
- To explore individual hopes and fears in relation to dying

Session 2: Getting our houses in order

Purpose:

- To discuss the importance of planning earlier for end of life
- To provide information upon Advance Care Directives (ACDs)
- To provide resources re ACDs and Funeral Planning

Session 3: What is Palliative Care? Where can services be accessed?

Purpose:

- To inform participants of the definition of Palliative Care
- To identify where and how Palliative Care Services can be accessed
- To provide resources upon Palliative Care
- To discuss the importance of memories and grief
- To gauge the need for further mentoring and supports from today

Implied aims associated with the training aspect of the event were to

- a) increase participant level of comfort in talking about death, dying, palliative care, and advance care planning
- b) demonstrate / model how to introduce and encourage similar conversations within their community; and
- c) increase participant confidence, skills, and knowledge to facilitate similar conversation/workshops within their community.

As this evaluation was to inform the continual development of a culturally appropriate training program, a developmental evaluative approach was applied. The following is a summary of data provided via a feedback form completed by participants (including observations on demographic characteristics), and observations made by JE on participant engagement during the workshop.

Participant Feedback

Before leaving, participants were invited to complete an evaluation form regarding their experiences and views of the workshop (see [Appendix E](#)). The form was divided into three sections:

- About the participants (demographic details, reported above);
- About the organisation of the workshop; and,
- Participant views on the workshop content.

Organisation of the Workshop

Participants were asked to indicate the extent to which they agreed with a series of six questions. Options were 1. Not at all; 2. Partly; 3. Fully.

Overall, feedback regarding the organisation of the workshop was overwhelmingly positive. Twelve participants fully agreed that the *information presented would help them educate their community* about the issues discussed; two indicated that this was partly true. All participants fully agreed that the *information provided was clear and easy to understand, the facilitator was knowledgeable and well-prepared, they felt comfortable asking questions, and that the event was well organised*. Finally, all but one fully agreed that *any questions raised were answered well*, with one indicating that this was partly true. There were no demographic factors shared by participants who did not fully endorse the statements.

Qualitative responses to invited for the *question What could we do to improve future workshops on these issues?* further reaffirmed the positive experiences of participants; more than half (8) left this blank, with two noting it was 'well planned' and 'well done.'

There were no consistent patterns in the suggestions for improvement were, though some of the points raised here were also mentioned at other points in the evaluation form. Individual suggestions are listed below.

- More legal concepts
- Need parking facility *
- Maybe a small short snippet about palliative care in a movie form or Youtube. Just to back up the monotony of the speaker asking us questions
- Do workshop in the community. The knowledge of palliative care is so important
- If the speaker can involve more practices in the speech, it will definitely help us understand the topic more deeply

* Participants were informed of the availability of reimbursement for parking, and, on request, were reimbursed at the time, or on provision of a parking receipt.

Content of the Workshop

Participants were asked to indicate the extent to which they agreed with a series of statement. Options were 1. Not at all; 2. Partly; 3. Fully. Community responses are provided in tables below, with green shading indicating '3-full agreement'; amber indicating '2-partial agreement'; and red indicating '1-no agreement.'

All agreed that the workshop helped them to *develop their understanding about the topic*; however, whilst most agreed that the workshop provided *a safe space to talk about death and dying*, two participants from the same ethnic community indicated that this was only partly true for them, and one of these only partly agreed that the *workshop had helped them develop new skills* (see table below). This points to the importance of follow-up to determine what conditions are required to create that safe space and facilitate the development of useful skills, specifically if a change in the content, pace, or environment may do so. It is noteworthy that respondents from this ethnic group were less likely than others to report being 'fully' informed or confident regarding other questions reported below. One other person indicated that they only partly felt they had developed new skills but noted later that they considered they had a high level of knowledge and skills already.

Statements. This workshop... [1-Not at all; 2-Partly; 3-Fully]

	...provided a safe space to talk about death and dying	...helped develop my understanding about new information	...helped me develop new skills that will be useful
Com 1	3	N/A	2
Com 1	3	3	3
Com 1	3	3	3
Com 2	3	3	3
Com 2	3	3	3
Com 3	3	3	3
Com 3	2	3	3
Com 3	2	3	2
Com 4	3	3	3
Com 4	3	3	3
Com 4	3	3	3
Com 5	3	3	3
Com 5	3	3	3
Com 5	3	3	3

Participants were then asked to rate their confidence in their knowledge and skills after the workshop (see Table below). A series of eight questions asked them to indicate the extent to which they agreed with statements listed below. For these questions, some participants wrote scores of 2.5, in addition to the provided range of 1-3; these are separately indicted, but with shading as per a rating of ‘2-partly.’

All, or most (14-15) felt confident that they knew *where to get information about palliative care, knew what an Advance Care Directive (ACD) was, and knew the benefits of completing an ACD*, suggesting that overall, the workshop was successful in increasing participants’ own knowledge. However, fewer reported full levels of confidence about the extent to which participants felt able to utilise this information in their community. For example, five participants (3 from one community and 2 from another) indicated that they only partly felt they could *identify and help their community overcome barriers to talking about death and dying*. The same individuals also reported feeling only partly or not at all confident that they *could open a discussion about dying, could clearly describe what palliative care was, knew the benefits of, or barriers to completing an ACD, or where to find information about ACDs*. The variation between communities regarding these responses indicates the importance of specific follow up to address the reported gaps in knowledge of confidence. Overall, however, responses suggested participants felt confident with the knowledge provided, but less confident regarding their ability to apply this knowledge in promoting discussions about death and dying within their community.

Statements: After this workshop I feel confident that I... [1-Not at all; 2-Partly; 3-Fully]

	...can identify and help my community to overcome barriers to talking about death and dying	...could open a discussion in my community about death and dying	...can simply and clearly describe what palliative care is	...know where to get more information about palliative care	...know what an Advance Care Directive (ACD) is	...know the benefits of completing an ACD	...can identify some barriers to completing an ACD	...know where to find information or resources about ACDs
Com 1	3	3	3	3	3	3	3	3
Com 1	2.5	3	2.5	3	3	3	3	3
Com 1	2	3	2.5	3	3	3	3	3
Com 2	3	3	3	3	3	3	3	3
Com 2	3	2	3	3	3	3	3	3
Com 3	2	1	3	3	3	1	2	3
Com 3	2	3	3	3	3	3	3	3
Com 3	2	3	2	3	3	3	2	2
Com 4	3	3	3	3	3	3	3	3
Com 4	3	3	3	3	3	3	3	3
Com 4	3	3	3	3	3	3	3	3
Com 5	3	3	3	3	2	3	2	2
Com 5	3	3	3	3	3	3	3	3
Com 5	3	3	3	3	3	3	3	3

QUALITATIVE RESPONSES were invited for 7 questions with up to three responses per question possible.

Question 1	No. of Responses				Total
	0	1	2	3	
What things were most helpful to your personally in this workshop?	1	6	3	4	14

The nature of what participant considered were helpful varied but can be divided into four topics. More than half noted that the *materials provided* were helpful, often referring to the *What Matters Most* cards used to start conversations; seven reported that *the interactive discussion* was helpful to gain a fuller understanding of the topic across their and other communities; finally, some noted that *specific topic knowledge or on how to locate useful resources* was helpful.

Topic (number of comments)

Materials used/provided (8)

cards; booklets provided; cards are helpful to start conversation; print materials

Workshop activities (including opportunity to share views) (7)

discussing topic; interactive form of workshop; group discussions; understanding differences in PC across communities; feeling common ideas with other communities; realising personal barriers on ACD.

Information on concepts (4)

explaining the concepts; statistics; enhancing my knowledge of PC

Information on resources (3)

learning what PC services are available; knowing how to find resources; Service Directories

Question 2	No. of Responses	0	1	2	3	Total
<i>From today's workshop, what things will help you the most to assist your community?</i>	-	8	4	4		16

Responses can be divided into five topics. Again, the provision of the *What Matters Most* cards was most often referred to, with some specifically noting the importance of *cards in their language*; others reported that *ideas and information about how to prompt or facilitate talk of death and dying*, and of *documentation regarding advance care planning* were useful.

Topic (number of comments)

Resources provided (5)

cards; what matters most card; service map; the powerpoint to share

Feeling prepared & able to start and have talks about death and dying (4)

able to discuss; start the discussion about death; ideas how to break the barrier for conversations; prepare, understand, and converse

Feeling prepared & able to help with documentation (4)

help people fill in ACD form; talk about importance of having documents in place

Cards in the language of their community (2)

having cards in my language; having resources in my language

Being able to offer Primary Palliative Care Services as a welfare centre (1)

Question 3	No. of Responses	0	1	2	3	Total
<i>Are there any topics about which you feel you need more information from MCCSA and PCSA before you hold your community forum?</i>	3	11	-	-		14

The specific topics for which participants felt the need for further information varied considerably, but two themes were evident: *Requests for more information on legal documentation (e.g. wills) at the end of life, and/or for more resources/information about services* (e.g. PCSA). This question prompted the fewest responses; three provided no answer here, with two specifically indicating that they felt they needed further time to reflect on this. This suggests that a more structured approach to exploring gaps in their knowledge (i.e., perhaps prompts of possible topics) and/or follow-up after participants have had some time to reflect may be useful.

- More clarity between role of will/ACDs/PC directives highlighting differences, for CALD communities
- Wills
- Legal info
- More information resources about ACP
- Preparation of handouts/resources and information packs (2)
- More information about PCSA roles and responsibilities
- How to access the services
- How to become a primary care provider

Question 4	No. of Response	0	1	2	3	Total
<i>What do you think will be your biggest challenges in talking with your community about death and dying?</i>	-	8	5	1		14

Identified challenges varied, but most focused on the *emotional and cultural barriers to talking about death within their community*. These included challenges in generating interest for a discussion about death and dying, specifically on how to identify the relevance of discussion for individuals regardless of age, concerns about

offending or upsetting individuals, cultural barriers to talking about death in general or in grasping what was meant by specific concepts (e.g. palliative care), and practical help with legal matters. Some of these barriers are not unique to culturally and linguistically diverse communities, but participants clearly felt the need for sensitive and culturally appropriate approaches to such discussions in their communities.

Topic (number of comments)

Lack of familiarity within community in talking about death (7)

we don't talk about death; they'd prefer to keep it 'out of sight, out of mind'; some people don't want to think about this; space to talk about death; the topic hasn't been talked about in community

Finding the right time and way to raise and generate interest in the discussion (6)

to know the right time for discussion; to find an appropriate time; those in reasonable health might feel they are not at the stage to deal with this; 'don't need to worry about it'; age; getting them interested enough to come to a session.

Concerns about offending, upsetting, or scaring people (4)

feels too morbid; not to offend anyone; not to scare people; sometime palliative care are taboo

Challenges identified as cultural (3)

cultural barriers; the fears of death in culture; some concepts like palliative care are not easily translated;

Others (2)

Some people need organisational skills to organise legal matters; preparation.

Question 5	No. of Response				Total
	0	1	2	3	
<i>What would help your community members to have conversations about death and dying</i>	2	9	4	-	15

Recommendations varied but included support for group events modelled on the current workshop, that included practical information, and language-based resources, perhaps including the presence of or promoted by respected community leaders. This suggests that a group workshop format led by an experienced facilitator was deemed to be an appropriate approach to broach these issues within community, whilst pointing to the need for other resources to support increasing community awareness.

Topic (number of comments)

Being present at a group event where death and dying were discussed openly (5)

being present somewhere the topic is being discussed in an open environment; going to established groups and talk about this issue; hopefully the forum will make people/wider community more aware of this topic; having it in a bigger group; forum – topics covered today to be held in a group to help those that are not comfortable talking about death

Inclusion of specific practical topics (3)

how to go about it, where to get help; talking about this topic from a legal way, how to access the resources and how to save money; talking about legal [matters]

Engaging religious community leaders (2)

priests talking to people; contact community leaders in religious organisation

Language-based resources (2)

brochures and printed articles in [my community language]; information written in [my community language]; help

Other (3)

community education; approach and help; [unclear statement]

Question 6	No. of Responses	0	1	2	3	Total
<i>What things would best help people in your community to have conversations about planning for the end of life?</i>	2	6	4	2	15	

Suggestions of what might be needed to help individuals to have conversations about planning for the end of life included facilitation of a safe and relaxed environment, regular opportunities to attend forums on the topic of death and dying, and working with people already involved in care or arrangements at the end of life. The most mentioned topic focused on practical issues for individuals, and the importance of tailoring the content of discussions to meet community interests. As the need for each community may vary, it will be important to work closely with community leaders/attendees to ensure the relevance of materials covered, and to provide opportunities for community members to identify their current needs.

Topic (number of comments)

Tailoring topics or process to meet community need or interest (6)

thinking about how this can help people and family to walk around the event and go to the next step; sit down with them on a one to one basis after the community presentation; legal matters; to be informed about PC; fill the will; fill in the Advance Care Form.

Ensuring that people felt at ease and wanted to be there (4)

getting people together in a relaxed atmosphere; feeling comfortable; knowing it's voluntary; knowing about the process

Scheduling (regular) community forums promoting such conversations (4)

community information sessions/forums; more community information sessions; forums; information sessions say once a year to people who want to

Working with people with an existing role, or existing groups, in community (4)

the funeral planer can help them arrange their planning; professional training for the community worker; go to established groups; identify community champions in this area and train them to go to community groups in [my community language].

Provision of brochures and pamphlets (2)

brochures in [my community language]; pamphlets

Question 7	No. of Responses	0	1	2	3	Total
<i>What things would best help people in your community to complete an Advance Care Directive?</i>	1	7	4	2	14	

Suggestions of things to help increase completion of ACDs in their community included provision of simple explanations and/or information about what an ACD was, and why it was important; availability of and assistance with understanding information in English and in their community's language; and encouragement generally or from trusted members of the community, including participants once they were more familiar with ACDs. Many responses highlighted a need for individualised support in completion of the form, particularly given statements that the form and/or instructions needed to be more 'simple,' juxtaposed with the legal requirement that the ACD form itself be completed in English.

Topic (number of comments)

Accessible information about ACDs (6)

Simple explanation of ACD; making people aware of ACD; clear detail and information can help them better understand what ACD is; simple version of ACD; simple explanation about what it is.

Assistance to manage the requirement that the ACD is written in English (6)

samples & info in their language; having the document in both language; develop a flyer in [community

language]; [community language] version of the form and handbook; have them in [community] language; help them in English

People and processes to encourage and guide people through completing the form (5)

to have someone trust to help guide them through the process; our older people; explain and encourage; discussion with priests/nuns.

Participants in workshop or others professionally trained (2)

Us, as community members, once we know ACDs well & understand scope & limits, we can tailor our communication within our community; professional training for the community worker

Other (2)

cards; to understand the importance of ACD, therefore to be well.

Finally, participants were asked if there were anything else they would like to add. 10 participants left this blank. Other comments were:

- *I thought the workshop was well run. If I said in my responses I didn't learn much that's only because I came with a high level of knowledge*
- *Good & informative workshop*
- *Lunch was great! Mark was fantastic! Isabella's organisation was great too!*
- *Group discussions were great. Extra reading material and cards will help with decision making. Visual, direct and detailed makes more sense, easier to follow.*

Evaluator Comments

The specific demographic characteristics of attendees may have implications for reported outcomes and/or for the process and outcomes of subsequent community workshops. These include that

- **Most participants were female**, which may have implications regarding cultural norms about the appropriate interactions and conversations between genders. Gender variability within ethnic groups during future training is recommended.
- **The level of prior exposure to and experience with conversations about death and dying varied**; for those with limited exposure, this may have limited the extent to which participants were able to reflect on the usefulness of the information for the purposes of assisting them to run equivalent workshops. In such cases, further individualised support may be required. For example, it may be useful to provide further opportunity or time to allow increased familiarity with the material, prior to training specifically on how to present this material to their community.
- Finally, although **some participants held leadership positions or were of an age that might endow them with some authority within community, others lacked either or both**. These latter (or similar others in future training) may require additional authoritative support to facilitate community workshops successfully and safely, particularly given known cultural practices in some communities that dictate appropriate and respectful modes of communication between individuals (e.g., based on gender, age, or professional role).

The following points are based upon evaluator observations of the workshop format, as well as participant engagement and contributions during the workshop.

- **Participants raised issues that were important to them**, not necessarily their community. For example, one participant consistently raised questions centred on procedural aspects of advance care planning. Careful consideration is needed to ensure that the interests and preferences of individuals do not compromise coverage of key points regarding, and sensitivity to, concerns and interests of community members attending the planned community forums.
- **Most information presented was text-based**, either written or spoken. Given varying levels of literacy likely present in community forums and capacity to engage with different modes of presentation (e.g.,

visual, verbal, kinaesthetic), some alternative modes of information presentation may increase accessibility. This might include use of videos, diagrams, images, or infographics.

- **The detailed information on palliative care was important, but not necessarily essential** to promoting and holding conversations about death, dying, and planning for the end-of-life. It covered a lot of information including complex definitions and where to find more information. At times, the conversation centred on these felt a little rushed and lacked depth. It may be more productive to separate out presentation of this information from the other materials presented, possibly thereby allowing further time for both.
- **The information and mode of presentation** allowed individuals to gain experiential knowledge and confirmation that conversations about death, dying, and planning for the end of life were possible and, contrary to some expressed fears, enjoyable and stimulating. This is a necessary but insufficient condition to enable them to take on a role of facilitating these conversations in their communities. Whilst several have professional knowledge to draw upon to help them manage possibly strong and conflicting opinions and associated emotions, not all did. Explicit training in this and/or the presence of those who can assist will be important to ensure the safety of all attending.
- **Similarly, it may be useful to explicitly identify and discuss barriers or challenges** participants might encounter when they are responsible for conducting the proposed community forums. Providing room for discussion on this, with structured opportunities to practice using 'scripts' or 'strategies' to help them to address or manage these, will minimise risk to themselves and others, and increase the likelihood of achieving the aims of the forum.
- **Some recognition of the importance of 'crowd control'** would better equip individuals to facilitate conversations that are potentially both intellectually and emotionally demanding. That is, participants may need guidance on facilitating communication in line with the agreed established norms. This might be in the form of instructions/advice/examples of: how to manage interactions that go beyond agreed norms; and, ensuring that the conversation stays focused on the purpose of the workshop, whilst simultaneously encouraging and validating participant views and keeping to a timetable.

Some of the above may be achievable through a 'meta-reflection' on the process and experiences of the participants, after the conclusion of the substantive content of the workshop. This should be facilitated by someone other than the workshop presenter and possibly in their absence to minimise either occasioning social desirability responding (i.e., only commenting on behaviour that was deemed helpful or appropriate) or embarrassment of either party (i.e. raising instances of talk or behaviour deemed less helpful or appropriate).

This could draw participant attention to the different behaviours of the facilitator that worked to (for example)

- engage participants
- invite different views
- refocus attention if it drifted
- achieve consensus
- check in with participants to ensure comfort and comprehension
- introduce new topics
- scaffold learning (link known to new information)
- validate participant views and experiences

Participants might also be invited to articulate things they noticed about what contributed to their positive outcomes and experiences. These could be collated and summarised with specific examples of and/or language around each of these techniques. This could be devised as a living document with additional information added as individuals reflected upon, captured, and shared what worked and what might require adjustment in their facilitation of community forums.

Stage 2: Community Forums with five CALD Communities

The following reports on Stage 2 of a collaboration between Multicultural Communities Council of SA (MCCSA) and Palliative Care SA (PCSA) in an SA Health-funded project entitled 'Courageous conversations with CALD Communities.' Following delivery of Stage 1, leaders/facilitators within each community undertook to disseminate the provided information within their own community through a Courageous Conversation Community (CCC) forum. Two Chinese language forums (Mandarin and Cantonese) were held, on advice from community. Additional activities were devised and delivered by and within community, according to community preferences and need between October 2020 and January 2021.

Given variation within the communities regarding available and/or preferred means of communication, the mode of delivery was tailored to meet specific community needs and/or preferences, scheduled in Jan 20221, sometimes during a regular meeting of community members. One community combined the information session with another addressing other sensitive issues, which limited the provision of specific feedback on the CCC forum element.

Each forum presented information in language (), some translating in real time from the Palliative Care SA (PCSA) speaker Mark Waters, others led by Community Workers and Leaders. Some communities included use of the language specific What Matters Most cards during the forum, but one provided this as a separate preliminary activity. Following each CCC forum, a series of questions were asked of the group with translation as needed (see below). Questions were based upon the objectives of the program and evaluator observations of the earlier 5-hour workshop.

Forum evaluation questions

- Were the goals and objectives clear?
- Was the information helpful
- Was this a safe space to talk about death and dying?
- Do you feel more able to talk with your family or others about death and dying?
- Were the cards (What matters most) helpful?
- Do you feel like you know more about palliative care now?
- Do you feel like you know more about Advance Care Directives?
- Do you think you could fill one in?
- What did you like best about today?
- What more would you like to know about these things?

Project objectives and outcomes

Objective: to demystify palliative care and advance care directives, and promote meaningful conversations about death and dying within each community

All reported that the sessions were clear, helpful, and that they felt better informed about advance care directives. There was less agreement that attendees felt confident to complete the Advance Care Directive (ACD) form, specifically because forms must be completed in English. Some commented on the usefulness of the What Matters Most cards in their own language, recommending that other information regarding palliative care and ACDs be provided in language.

Most valued the additional information provided regarding palliative care and palliative care services; one community commented that the amount of information presented through reviewing palliative care websites was overwhelming, although comments in another indicated that they felt able to navigate this information. Notwithstanding endorsement of the value of the information provided, feedback was mixed regarding participants' views on whether they felt better able to have conversations about death and dying with family or others. While some communities, and some members within communities, expressed confidence in their ability to have such conversations, some were less confident. This suggests that additional resourcing is required to support the initiation and successful conduct of such conversations.

Communities identified different topics for which they would like further information, though this varied across communities, indicating the need for ongoing community consultation to ensure that community needs are addressed. Suggested further topics included:

- more information about hospices
- clarification about differences between ACDs and other legal documents (e.g., Wills, Power of Attorney)
- meaning of terms such as 'end of life'
- specific conditions attached to palliative care, including costs, and how to access this
- current status of euthanasia and assisted death, especially regarding ACD and palliative care.

Objective: to promote and facilitate the delivery of targeted, appropriate information to communities via community identified and endorsed mechanism

Each community designed and delivered a series of tailored activities to increase awareness of ACDs and palliative care, as well as increase community familiarity and ease of engagement with conversations regarding death and dying. Activities featured a range of modalities utilising written, audio, and interactive engagement, and included:

- Community forums
- Radiobroadcast, with talk-back options available and opportunity to seek additional information afterward
- Radio podcasts in language via language radio programs over several weeks
- Development of specialised webpages
- Articles in community newsletters (online and hardcopy, some with national coverage), some with
 - 'searchword' games to increase familiarity with palliative care terminology
 - texts of podcasts
- Posters, flyers, and other promotion
- Information sessions in language-based schools
- Distribution of Palliative Care packs to eligible elders, with additional information in language

Objective: to create connections between PCSA, MCCSA and CALD communities and CALD community members interested in or concerned about palliative care.

Increased connections between the above entities was evident both during and after the completion of the CC forums. Several representatives of the communities were seen to approach Mark Waters at the end of the session and request further meetings to help them in the delivery of targeted information to their communities. Similarly, individual communities liaised with MCCSA to design and create such materials, notwithstanding that some communities independently developed and ran information-sharing sessions via multiple and varied mechanisms, as noted above.

Conclusion and recommendations

The objectives of this stage of the project were met. Led by the facilitators/leaders who had attended the initial workshops, each community demonstrated enthusiasm and commitment in considering how to best tailor and adapt the information provided to maximise reach and relevance. Both MCCSA and PCSA facilitated this, providing resourcing and personnel time to support community activities. This outcome was significantly reliant on the trust and goodwill inherent in the extensive existing relationships and network between the individuals and organisations involved. In this MCCSA played a pivotal role in introducing and supporting communication and interactions, acting as a bridge between PCSA and the CALD community-based organisations.

Stage 3: Community Knowledge, Attitudes, and Practices before and after Project

Two activities were conducted as part of Stage 3.

1. A KAP survey was circulated to and within each community in January 2021, with results compared with those obtained in September 2020.
2. Five community focus groups were conducted in March 2021. These were designed and facilitated by the evaluator, with questions focused on the stated objectives for the overall project. All but one was also attended by Isabella Bracco (MCCSA). Groups were conducted in March 2021 at a time and place nominated by each community. All forty-eight participants provided signed informed consent to audio-record each discussion for review and analysis.

Survey Methods

Twenty-nine multiple choice, closed, and open-ended questions were circulated within communities. Questions were designed to assess community Knowledge, Attitudes, and Practices (KAP) regarding Advance Care Directives (ACDs), Palliative Care, and talking about Death and Dying. Community, gender, and age range were also collected.

MCCSA provided the survey online as a “google form,” as well as in Word and PDF formats for those communities that preferred to print it out and have them filled into through a hard copy. Two communities used the former, and three the latter, method.

The nominated community leaders/facilitators within each community circulated the information and survey (link or hard copy). No attempt was made to match participant responses across the two timelines. Individual survey responses were collated into community-responses within an Xcel Spreadsheet by the Project Manager at MMCSA, then provided to the evaluator for analysis.

Pre-intervention and post-intervention data were assumed to be independent for the purpose of statistical analysis. When the results (e.g., demographic variables) were not expected to be affected by the intervention, pre- and post-intervention data were pooled for analysis. Chi square analyses were used to determine whether differences in proportions from pre- to post-intervention and between community groups were statistically significant (that is, whether differences observed in the sample were likely to represent true differences in the population being studied). For continuous data, Mann-Whitney U-tests were used. No adjustments were made for the number of inferential tests being run. Furthermore, due to the size of the sample, no statistical adjustment was made for the hierarchical effect of the community groupings except where this was being studied directly. The statistical significance of the results should therefore be interpreted conservatively.

Focus Group Methods

Guided by Project Objectives as stipulated in the Project Grant Proposal, focus group questions were designed to address outcomes of the project activities, including participant:

- awareness and perception of community-led activities conducted as part of the project
- views on the extent and nature of subsequent conversations regarding ACDs, Palliative Care, and talking about death and dying
- awareness and understanding of ACDs and Palliative Care
- awareness of resources relating to the above
- identification of barriers to discussions regarding palliative care and/or completion of ACDs
- recommendations on how to continue to promote project objectives

As in Stage 2, the mode of delivery was tailored to meet specific community needs and/or preferences, sometimes scheduled as part of a regular meeting of community members. Questions were provided in English, with most participants responding in English. In some sessions, translation was provided and interwoven with the discussion, with some side conversations held in language to clarify meaning; in one, questions and answers were translated by a senior community member, with no group discussion in English.

Each session commenced with introductions, a summary of the progress and feedback from their community thus far, and reiteration of the conditions and purpose of the focus group. The number of persons attending were 7, 7, 9, 12, & 13 (48 in total). Session ranged from 55 to 100 minutes in length, with an average time of 1hr 16 minutes.

Focus group evaluation questions

- Since the project began, where have you heard or seen any further information about these things?
- If someone asked you to explain the difference between a Will and an ACD, what would you say?
 - Why do you think you might complete an ACD? Why not?
- If you had a friend with a dying loved one/family member, and they seemed to be struggling, (how) could you tell them about palliative care and what supports might be available?
- What stood out to you about these messages? What was the most important thing you learned since we began the project?
- What can MCCSA and PCSA do to help your community with these things?
- Is there anything else you think we should know?

Prompt questions

- Can you tell me a little more about that? Do you have any examples?
- Does anyone else have anything to add to those thoughts?
- Does anyone have a different experience to share?

Survey Results

A total of 185 surveys were returned, with all communities providing slightly fewer surveys post-intervention compared with pre-intervention numbers.

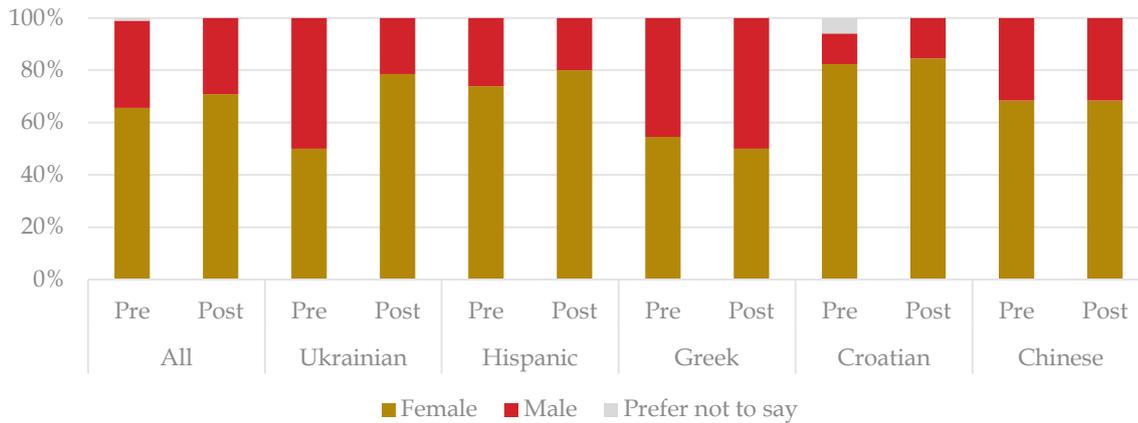
COMMUNITY	NO. SURVEYS RETURNED		
	Pre	Post	Total
<i>Chinese</i>	19	19	38
<i>Croatian</i>	17	13	30
<i>Greek</i>	22	20	42
<i>Hispanic</i>	23	20	43
<i>Ukrainian</i>	18	14	32
TOTAL	99	86	185

Approximately two-thirds of respondents were female (65.7% pre-intervention, 70.9% post-intervention). The Greek cultural group had a more equal ratio of males and females, approaching 50:50, whereas the Hispanic and Croatian groups were more heavily weighted with females, who made up around 75% of those samples.

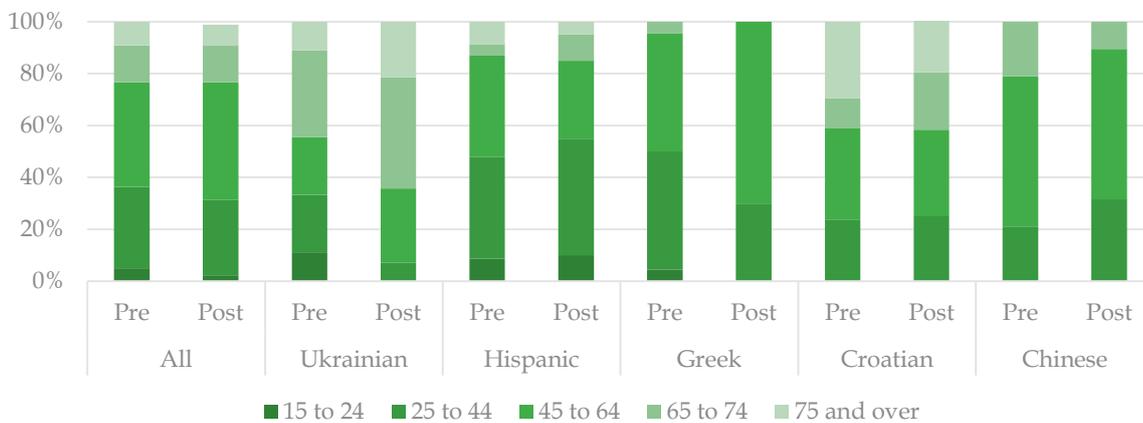
The main age ranges represented were 25-44 and 45-64, which comprised around three quarters of the sample. The age ranges sampled appeared to be relatively consistent between pre- and post-intervention measures within each cultural group.

There were substantial differences between cultural groups: the Greek group were almost all aged under 65, while the Chinese group had no respondents aged over 74. However, the Croatian and Ukrainian groups had greater representation of the older age ranges. An important implication of age and gender differences between cultural groups is that these structural differences could explain any differences observed in other questionnaire responses. This plus the small sample sizes within each cultural group makes it hard to reliably detect any true differences between cultural groups.

Respondent gender by cultural group and time



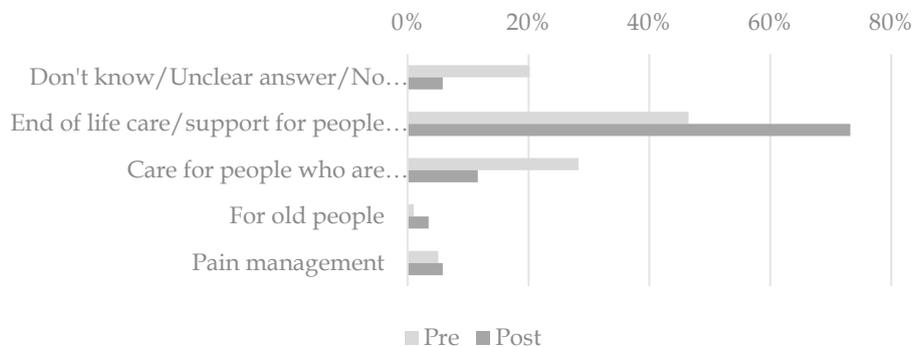
Respondent age by cultural group and time



Knowledge about palliative care

The proportion of respondents with an accurate understanding of palliative care (i.e., meaning end of life care/support for people who are terminally ill and facing death) increased from 46.5% prior to the intervention to 73.3% post-intervention, a statistically significant increase.¹

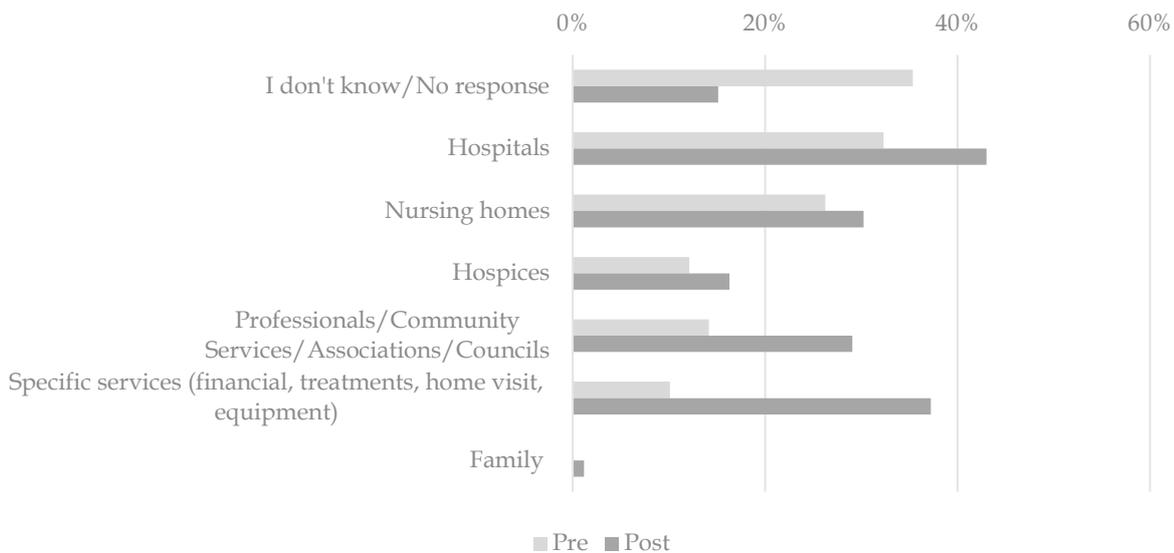
What do you think palliative care is?



¹ $\chi^2(1) = 14.15, p < .001$

Prior to the intervention, respondents were most familiar with palliative care services such as hospitals (32.3%) and nursing homes (26.3%). There was a lower awareness of other services including professionals / community services / associations / councils (14.1%), hospices (12.1%), and specific services (10.1%). The proportion of respondents who did not know of any services or did not respond fell from 35.4% prior to the intervention to 15.1% post-intervention, a statistically significant decrease.² This was matched by increases in awareness of all types of services providing palliative care.

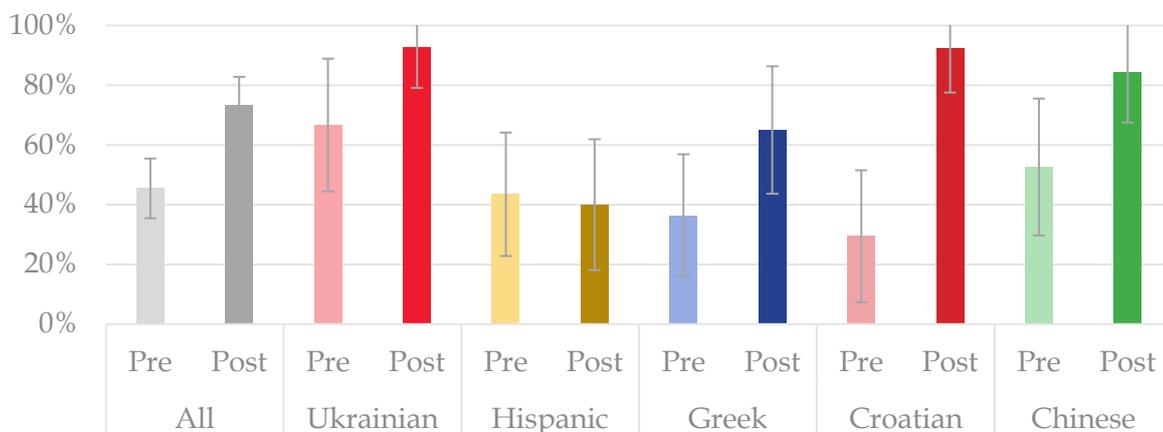
Which services do you know of that provide palliative care for people facing death?



Knowledge about Advanced Care Directives

Prior to the intervention, 45.5% of respondents reported knowing what an Advanced Care Directive was. Post-intervention this improved to 73.3%, a statistically significant increase.³ The increase appeared particularly marked in the Croatian community (+41.2%).

Know what an Advanced Care Directive is

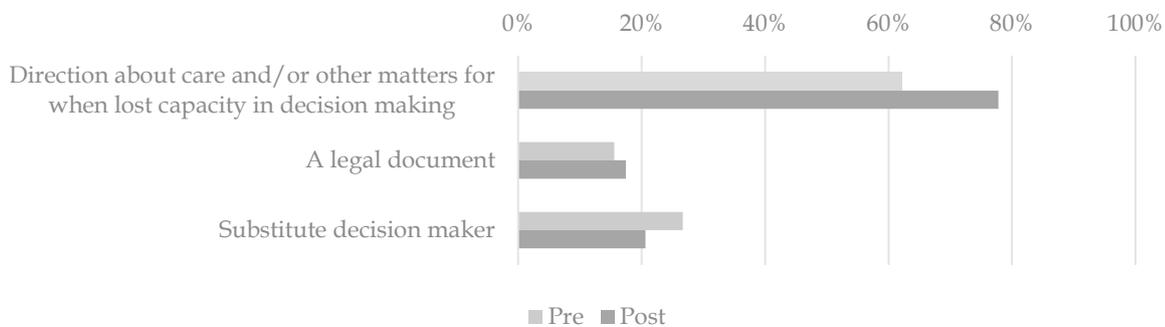


² $\chi^2(1) = 9.81, p = .002$

³ $\chi^2(1) = 14.64, p < .001$

Of the participants who reported knowing what an Advanced Care Directive was, 62.2% were able to identify that this encompassed directions about care and/or other matters for when decision-making capacity was lost. Post-intervention, this proportion increased to 77.8%, a statistically significant change.⁴

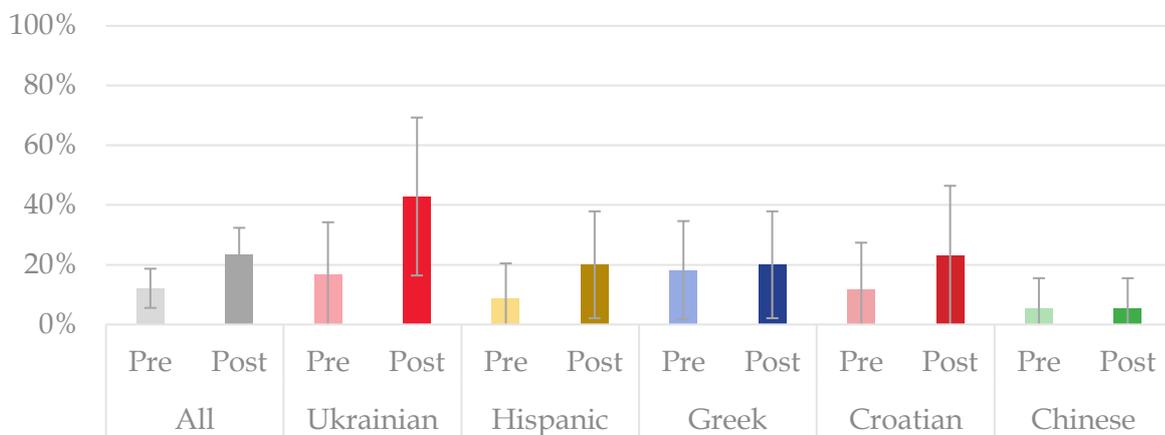
What is your understanding of an Advanced Care Directive?



Completion of an Advanced Care Directive

Prior to the intervention, only 12.1% of respondents reported having completed an Advanced Care Directive. Post-intervention this improved to 23.3%, a statistically significant increase.⁵ The increase appeared particularly strong in the Ukrainian community (+26.2%).

Completed an Advanced Care Directive



Of the respondents who stated pre-intervention that they had not completed an Advanced Care Directive, 39.5% said that this was because they did not know what it was. Other common reasons cited include no perceived need due to being too young, early, or healthy (22.2%) and having never considered it (13.6%). Following the intervention there was a large, statistically significant⁶ reduction in the proportion who reported not knowing what an Advanced Care Directive was (-31.7%). There was also a statistically significant⁷ increase in the proportion of respondents who indicated they were too young or healthy (+18.4%). The proportion of respondents who stated they were considering completing an Advanced Care Directive increased from 2.5% pre-intervention to

⁴ $\chi^2(1) = 9.13, p = .003$

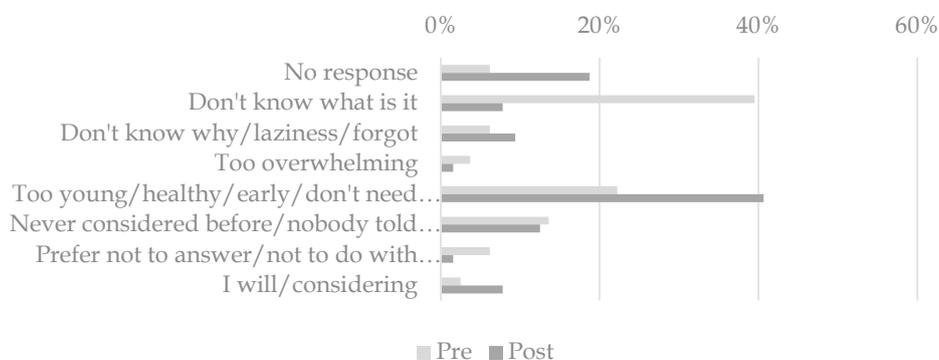
⁵ $\chi^2(1) = 4.18, p = .041$

⁶ $\chi^2(1) = 19.05, p < .001$

⁷ $\chi^2(1) = 6.00, p = .014$

7.8% afterward, but this change was not statistically significant.⁸ There were only minor changes in all other response categories. Data on individual communities were too sparse to be able to identify any differences in reasons for not completing an Advanced Care Directive.

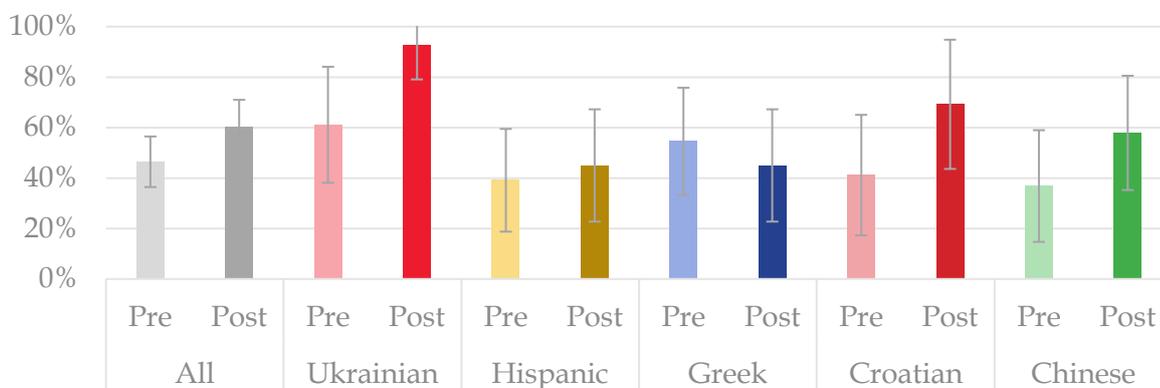
Reasons for having not completed an Advanced Care Directive



Communicating care needs

Prior to the intervention, 46.5% of respondents reported that others would know what care they would want if they became too unwell to say it. Post-intervention this improved to 60.5%, a statistically significant increase.⁹ The increase appeared particularly strong in the Ukrainian (+31.8%) and Croatian (+28.0%) communities.

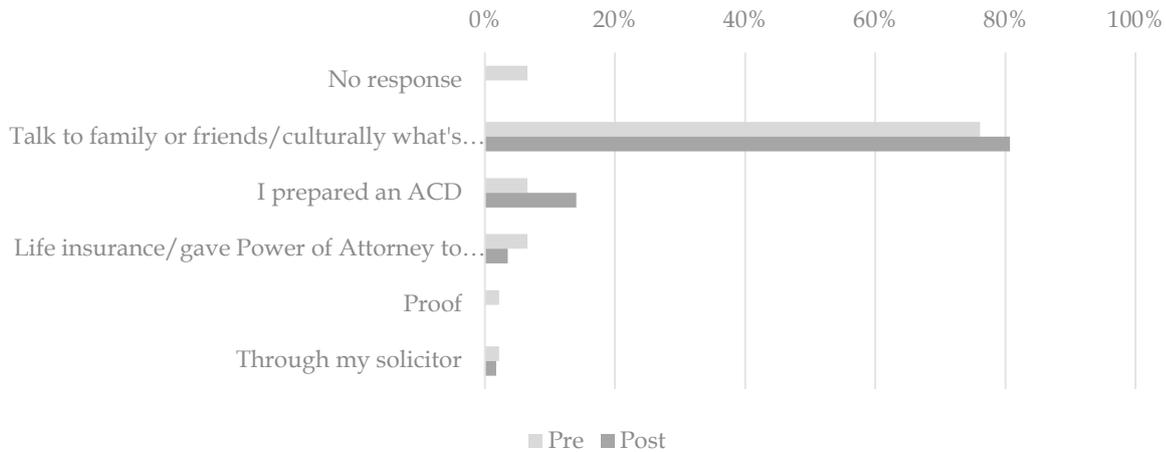
Others know what care you would want if you became too unwell to say it



Respondents were asked how others knew about what care they desired if they became too unwell to say it. For the majority (76.1%), this was through talking to family or friends, or already established cultural conventions. Pre-intervention, a small proportion of respondents (6.5%) had communicated their desired care through an Advanced Care Directive. This proportion more than doubled following the intervention (14.0%), a statistically significant increase.¹⁰ Other methods of communicating desired care changed only minimally from pre- to post-intervention. There were insufficient data to detect differences between individual communities.

⁸ $\chi^2(1) = 2.52, p = .112$
⁹ $\chi^2(1) = 4.49, p = .034$
¹⁰ $\chi^2(1) = 4.74, p = .029$

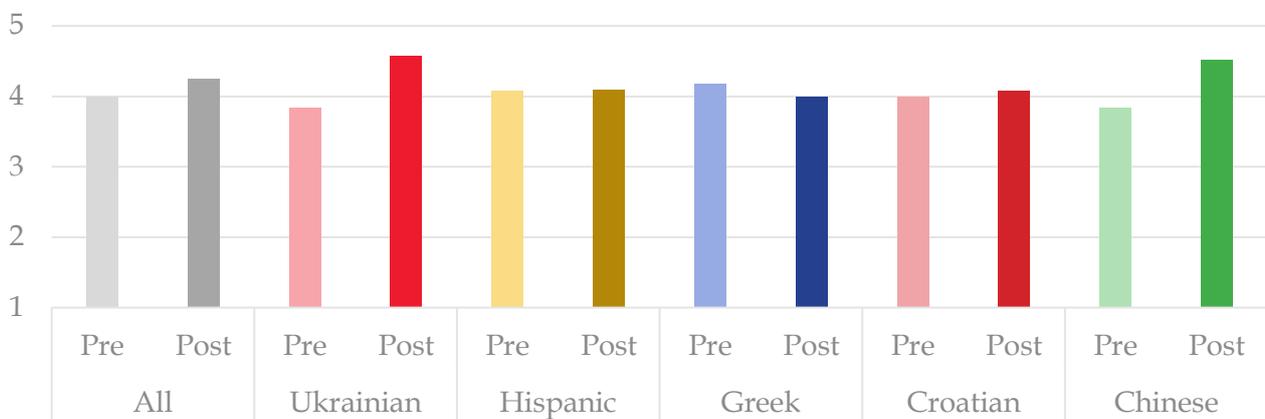
How others know about care desired if too unwell to say it



Discussing death and dying with others

Respondents reported their level of comfort in speaking about death and dying as an individual, within their family, and within the wider community (where 1 corresponds to *not at all comfortable*, and 5 signifies *complete comfort*). The mean level of individual comfort was 4.00 prior to the intervention, increasing somewhat to 4.24 post-intervention, though the increase was not statistically significant.¹¹ A similar pattern of increases was seen at the family (3.68 rising to 4.01)¹² and community (3.54 rising to 3.87)¹³ levels.

Comfort speaking about death and dying *as an individual* (1 = Not at all, 5 = Completely)

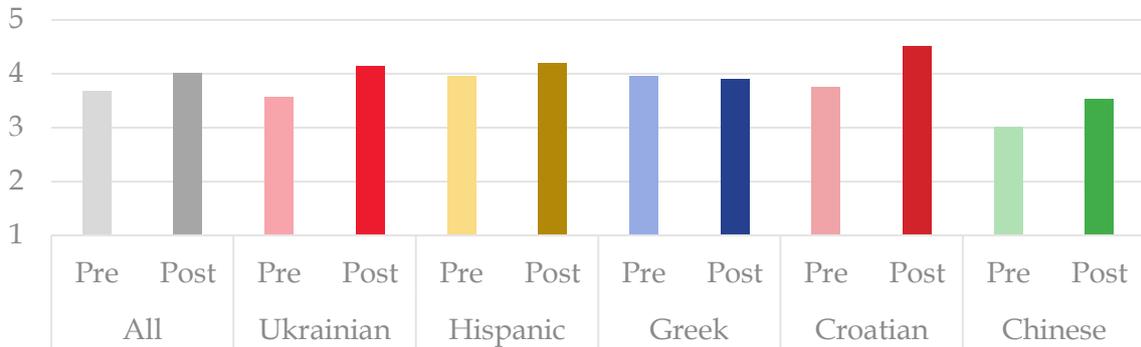


¹¹ $U = 3838, p = .160$

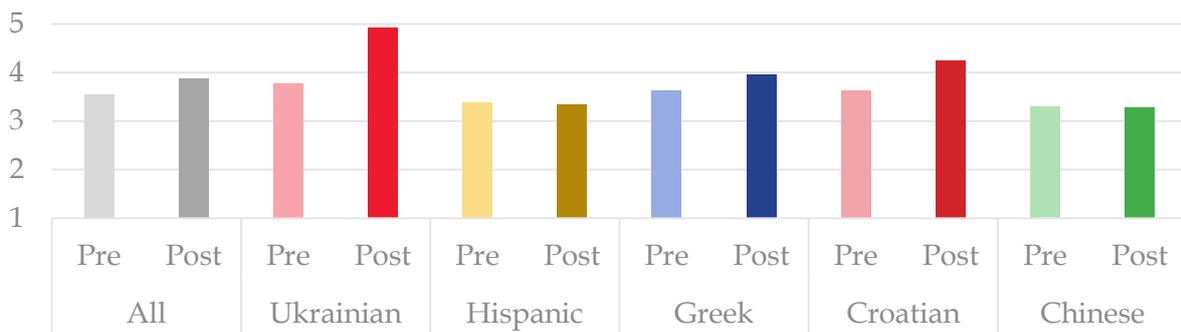
¹² $U = 3622, p = .169$

¹³ $U = 3616, p = .207$

Comfort speaking about death and dying *within your family*
(1 = Not at all, 5 = Completely)

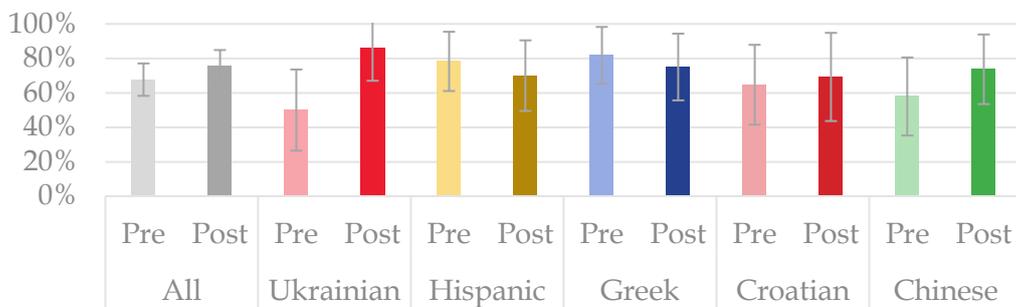


Comfort speaking about death and dying *within wider community*
(1 = Not at all, 5 = Completely)



Approximately two-thirds (67.7%) of respondents initially reported having discussed their thoughts of death or dying with someone else. This increased to around three-quarters (75.6%) following the intervention, although the change was not statistically significant.¹⁴ The increase was most notable within the Ukrainian community (+35.7%).

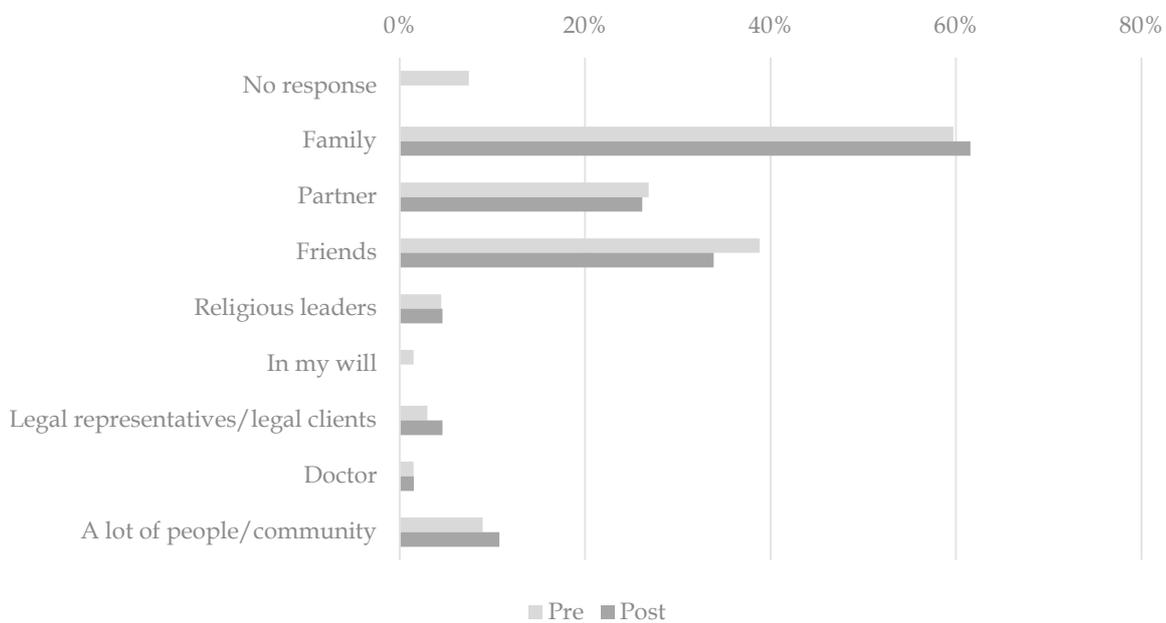
Ever discussed thoughts of death/dying with someone



¹⁴ $\chi^2(1) = 1.75, p = .186$

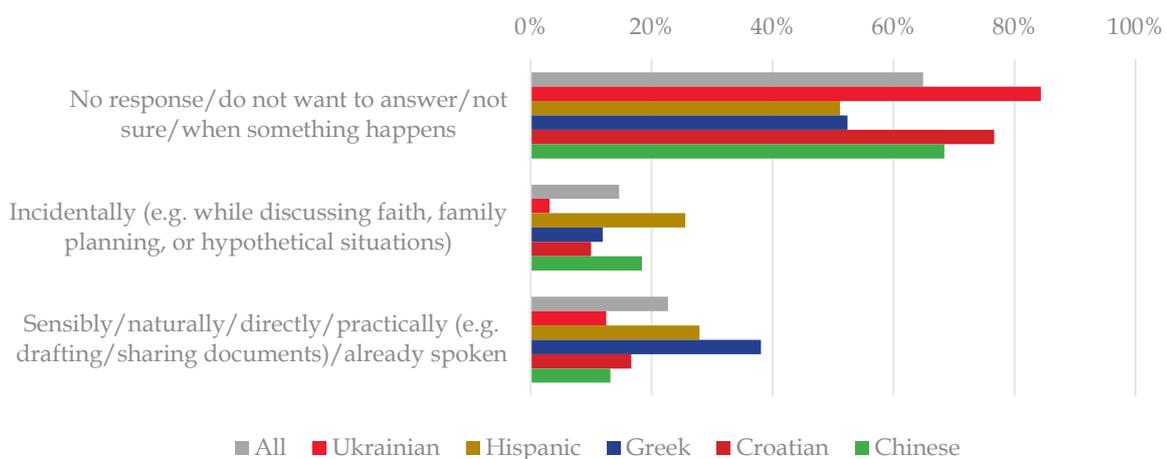
Death or dying was most commonly discussed with family members (59.7% of respondents), followed by friends (38.8%) or partners (26.9%). Fewer respondents reported having spoken to their wider community (9.0%), religious leaders (4.5%), legal representatives (3.0%) or doctors (1.5%). There was minimal change in these proportions (<5%) following the intervention.

Death/dying was discussed with...



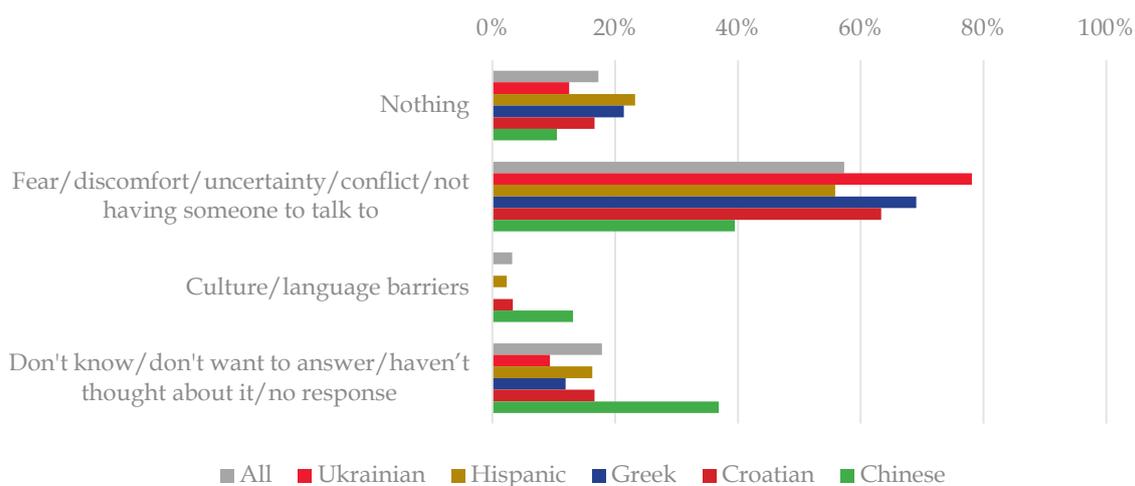
The majority of respondents (64.9%) did not respond or were unsure when they would initiate a conversation about death or dying with family. Around a quarter of respondents (22.7%) preferred to initiate a conversation sensibly, naturally, directly, or practically. A further 14.6% preferred to do so incidentally, such as when discussing related topics.

Preferred ways to initiate a conversation about death/dying with family



Overall, 17.3% of respondents said that there were no barriers to speaking about death/dying. The most common perceived barriers were fear, discomfort, uncertainty, conflict, or not having someone to talk to (57.3%). Few participants (3.2%) felt that cultural or language barriers would be a barrier. Around one in six respondents (17.8%) did not know, did not want to answer, or had not thought about possible barriers. The proportion of respondents who reported no barriers did not vary significantly across cultures.¹⁵ However, the proportion of respondents reporting fear, discomfort, uncertainty, conflict, or not having someone to talk to was significantly related to culture,¹⁶ with Ukrainians endorsing this most strongly (78.1%) and Chinese most weakly (39.5%). The proportion of respondents who did not know, did not want to answer, or had not thought about possible barriers was also significantly related to culture,¹⁷ with Chinese respondents endorsing this much more often (36.8%) than others. The association between culture and cultural or language barriers could not be statistically tested due to the low frequency of responses.

Perceived barriers to speaking about death/dying



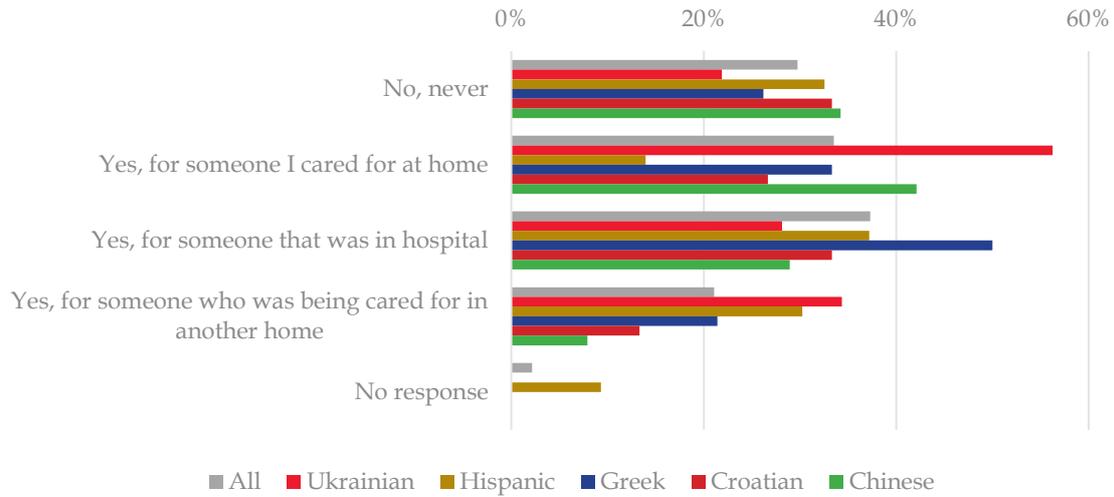
Experience of the death/dying process

29.7% of respondents indicated they had never previously gone through the death/dying process with another. About a third (33.5%) experienced this with someone they cared for at home, a third (37.3%) with someone who was in hospital, and around a fifth (21.1%) with someone being cared for in another home.

The proportions of respondents who had never cared for another¹⁸ or had cared for someone in hospital¹⁹ did not vary significantly across cultures. However, culture was significantly associated with the proportion of respondents who cared for someone else at home²⁰ and in another home,²¹ both being more common within Ukrainian respondents.

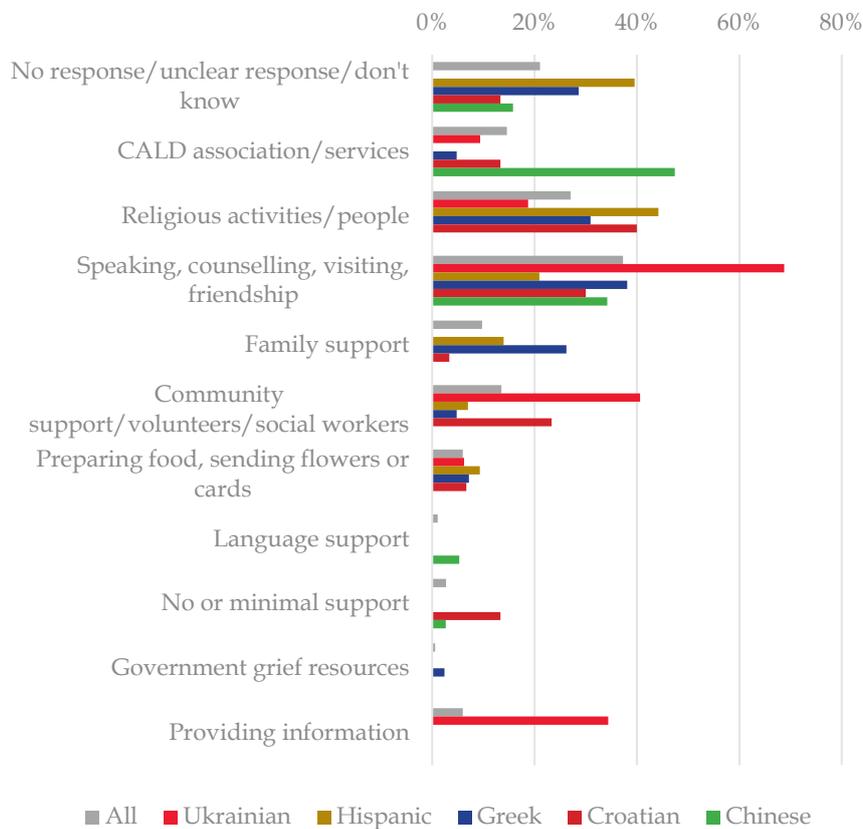
¹⁵ $\chi^2(4) = 3.31, p = .508$
¹⁶ $\chi^2(4) = 12.97, p = .011$
¹⁷ $\chi^2(4) = 11.72, p = .020$
¹⁸ $\chi^2(4) = 1.91, p = .752$
¹⁹ $\chi^2(4) = 5.36, p = .253$
²⁰ $\chi^2(4) = 16.70, p = .002$
²¹ $\chi^2(4) = 10.40, p = .034$

Experience going through the death/dying process



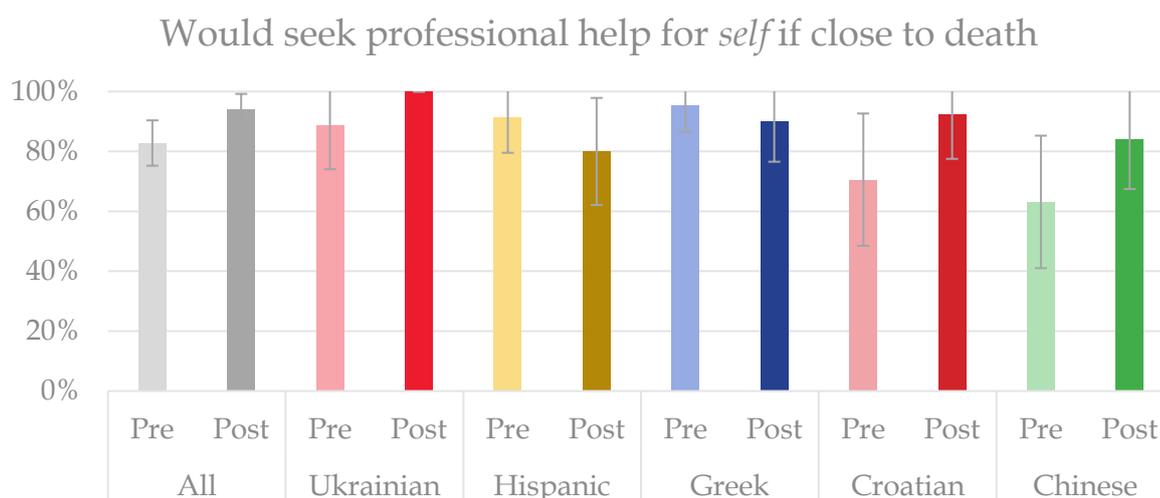
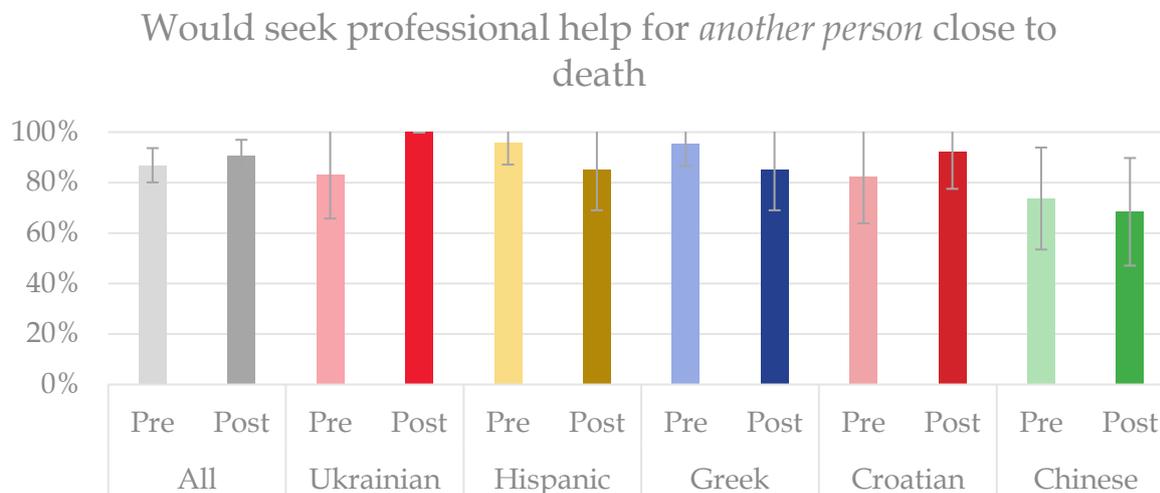
The most common type of community support for those who are grieving was speaking, counselling, visiting, and friendship, endorsed by 37.3% of the sample. Other commonly used methods of support included religious activities and people (27.0%), CALD associations and services (14.6%), community support/volunteers/social workers (13.5%), and family support (9.7%). Substantial heterogeneity was evident between cultural groups in terms of the commonly used support methods. For example, nearly half (47.4%) of Chinese respondents indicated the use of CALD associations or services, around two-thirds (68.3%) of Ukrainian respondents endorsed the use of speaking, counselling, visiting, and friendship.

How does your community support those who are grieving?



Accessing professional help

A large majority of respondents stated that they would access professional help if someone close to them was near death (86.9%) or if they themselves were close to death (82.8%). These proportions rose following the intervention (+3.8% and +5.4% respectively), but the increases were not statistically significant.²²



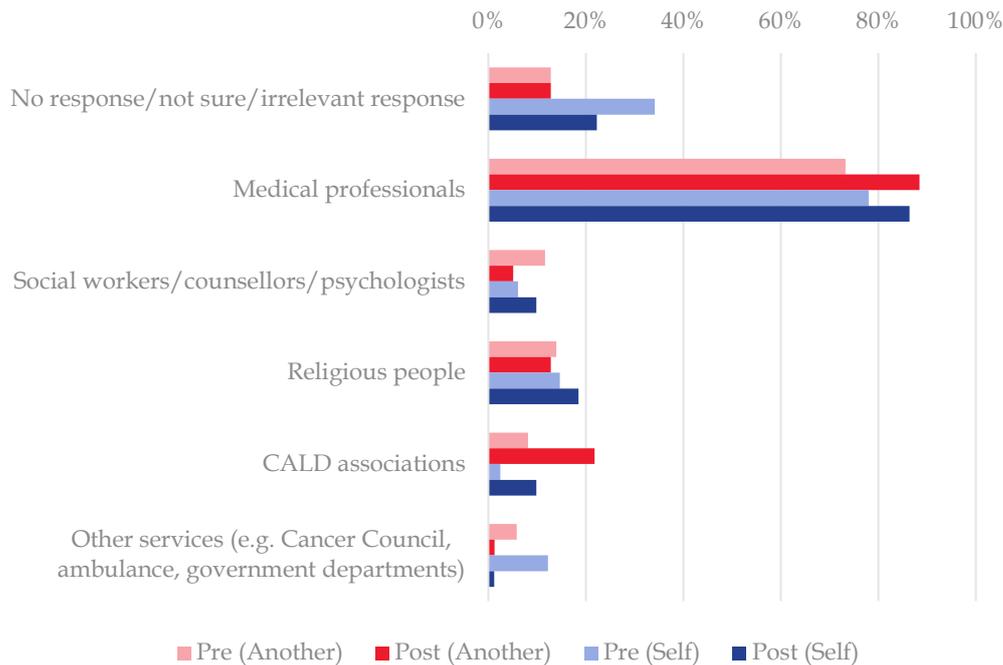
Prior to the intervention, the most common kind of professional desired was medical professionals (73.3% of those who desired professional help for others and 78.0% of those who desired professional help for themselves). Religious people, social workers/counsellors/psychologists, CALD associations, and other services were much less frequently nominated (typically <20%). The proportion of respondents desiring the help of medical professionals increased substantially for another person (+15.2%) and for self (+8.4%), though only the former increase was statistically significant.²³ Desire for assistance from CALD associations also increased significantly in regard to both self (+7.5%) and another person (+13.7%),²⁴ but there were only minor changes in other types of help desired. There were insufficient responses to detect any differences between cultural groups in terms of the desired type of professional help.

²² $\chi^2(1) = 0.09, p = .770$; $\chi^2(1) = 1.73, p = .188$

²³ $\chi^2(1) = 6.11, p = .013$; $\chi^2(1) = 2.64, p = .104$

²⁴ $\chi^2(1) = 4.61, p = .032$; $\chi^2(1) = 6.20, p = .013$

Type of professional desired



Respondents appeared to wish for similar types of assistance from professionals when thinking about their own needs and those of another person. For respondents who desired assistance from professionals, the most commonly desired types of assistance were treatments (>70%), pain management (>60%), access to equipment (>60%), emotional support (>55%), and spiritual guidance/support (>50%). Less commonly desired supports were financial or economic support (>40%) and grief and potential loss management (>35%).

Desire for grief and potential loss management for the self increased significantly from pre- to post-intervention (+20.3%), but there was no significant change in regard to another person.²⁵ Desire for pain management for another person decreased significantly (-15.2%), though there was no change in desire for pain management for the self.²⁶ Desire for spiritual guidance/support,²⁷ treatments,²⁸ financial or economic support,²⁹ emotional support,³⁰ and access to equipment³¹ did not change significantly in relation to either another person or the self.

²⁵ $\chi^2(1) = 7.38, p = .007; \chi^2(1) = 0.88, p = .349$

²⁶ $\chi^2(1) = 4.55, p = .033; \chi^2(1) = 0.72, p = .395$

²⁷ $\chi^2(1) = 0.85, p = .355; \chi^2(1) = 1.42, p = .234$

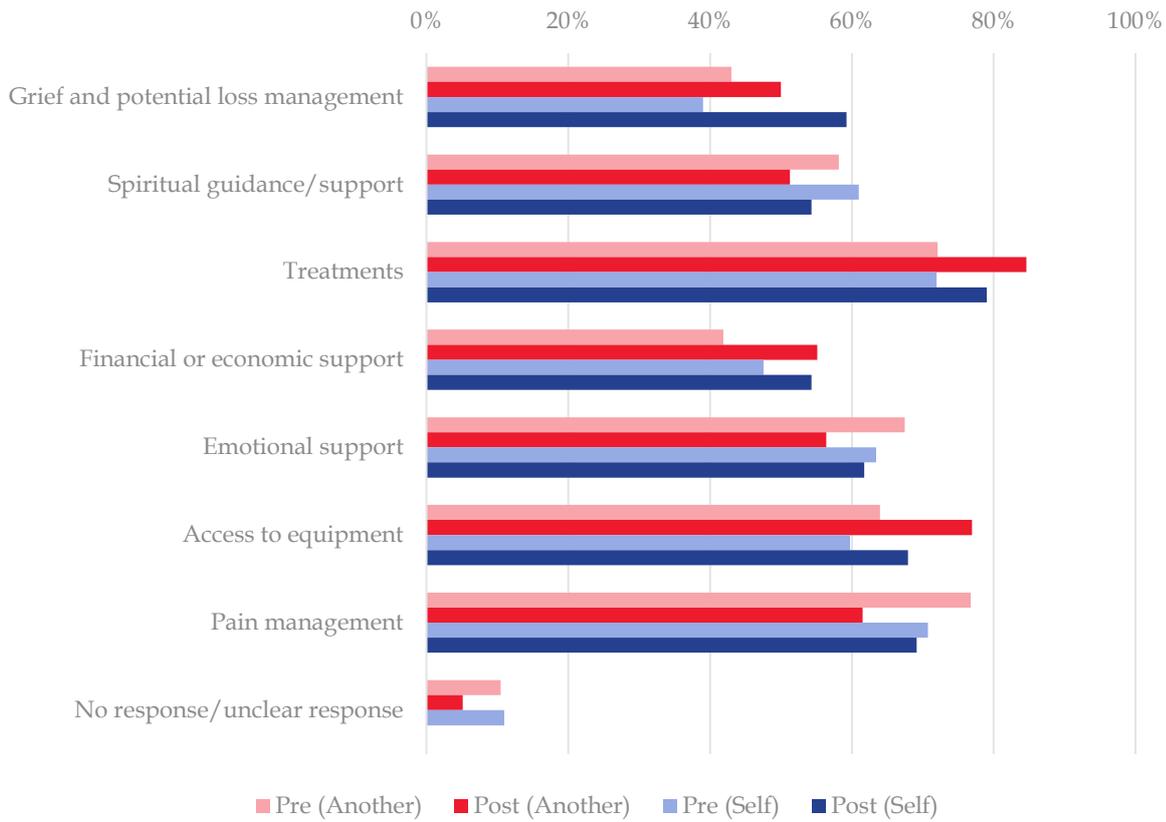
²⁸ $\chi^2(1) = 3.83, p = .050; \chi^2(1) = 1.78, p = .183$

²⁹ $\chi^2(1) = 2.97, p = .085; \chi^2(1) = 1.42, p = .233$

³⁰ $\chi^2(1) = 2.20, p = .138; \chi^2(1) = 0.72, p = .395$

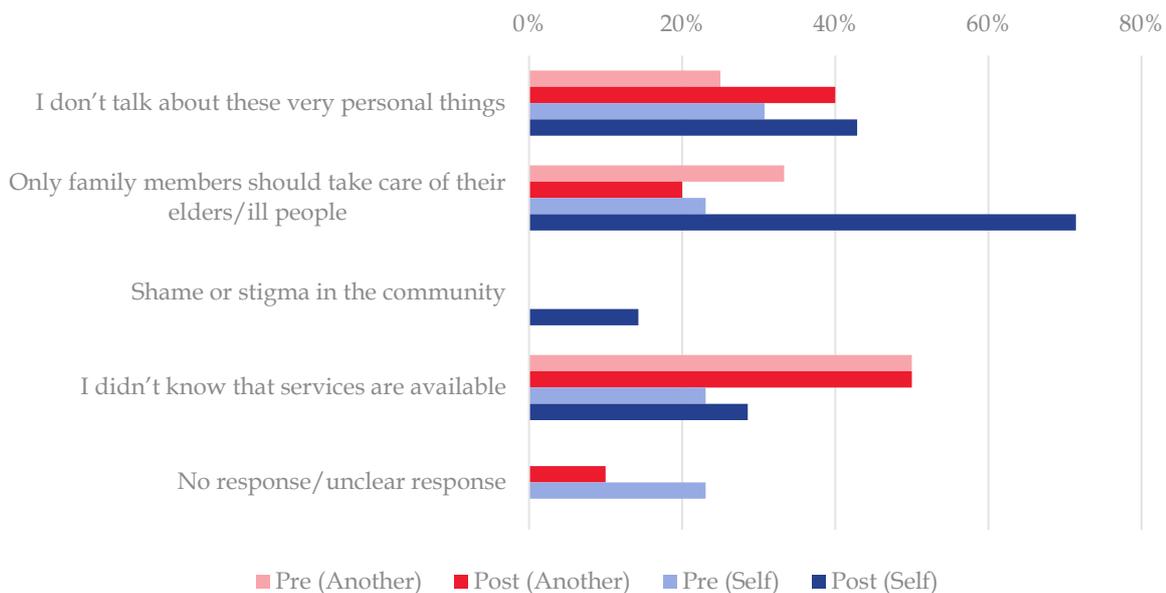
³¹ $\chi^2(1) = 3.37, p = .066; \chi^2(1) = 1.85, p = .174$

Type of assistance desired from professionals



Participants who did not desire professional help for another person (n = 12 pre-intervention, n = 10 post-intervention) or for themselves (n = 13 pre-intervention, n = 7 post-intervention) were asked to describe reasons why they would not seek such help. The most commonly endorsed reasons were a lack of awareness of the help available, not wanting to discuss such personal issues, and a belief that these problems should be managed by family. Due to the small number of responses, inferential statistics could not be used.

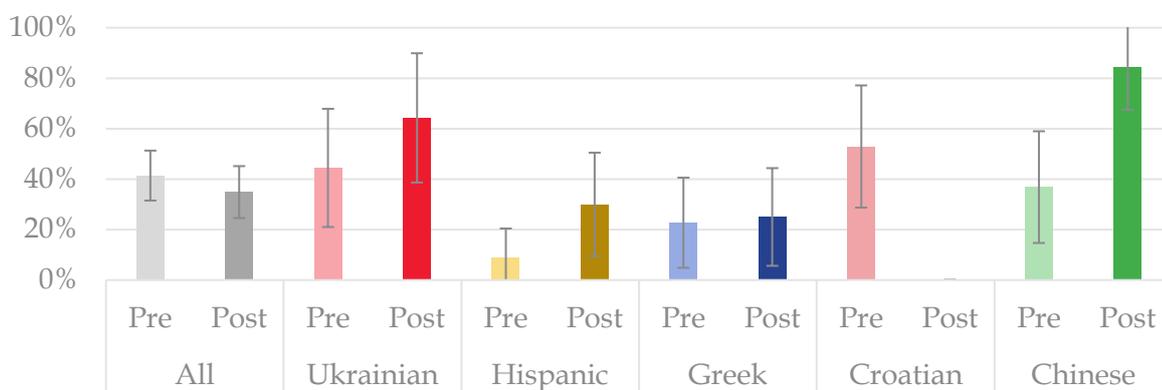
Reasons for not desiring professional help



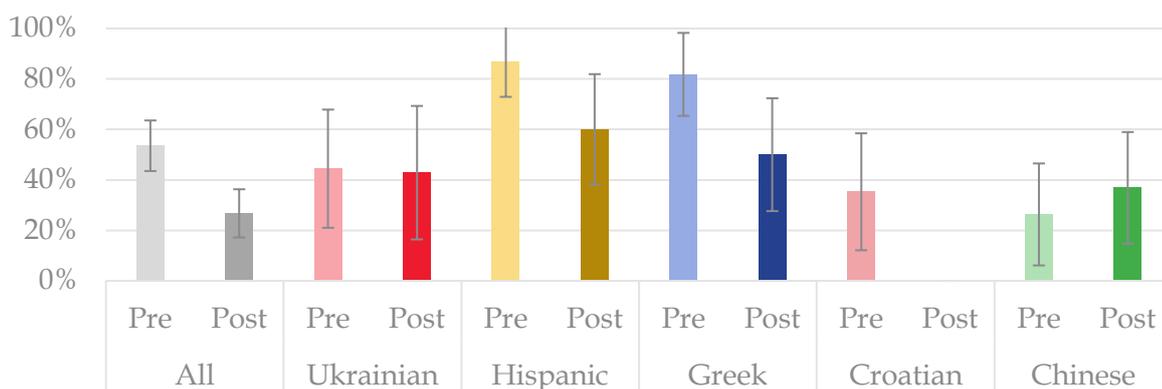
Barriers to accessing support services

Respondents were asked to indicate barriers that might get in the way of accessing services if there was a need for them. Perceptions of these access barriers appeared to vary substantially by culture. Language difficulties appeared to be a more common problem for Ukrainian, Chinese, and Croatian communities, whereas less than 30% of those in Hispanic and Greek communities considered this to be a barrier. Lack of knowledge about services seemed to be a major barrier for Hispanic and Greek communities, with over 80% of respondents endorsing this problem prior to the intervention. Even in Ukrainian, Croatian and Chinese communities, a lack of knowledge about services was considered to be a barrier by around 30-40% of respondents. Overall, 53.5% of respondents stated that a lack of knowledge about services was a barrier prior to the intervention, and this decreased significantly to 26.7% in post-intervention ratings.³²

Barrier to accessing services: Language/English not a first language



Barrier to accessing services: Lack of knowledge about services

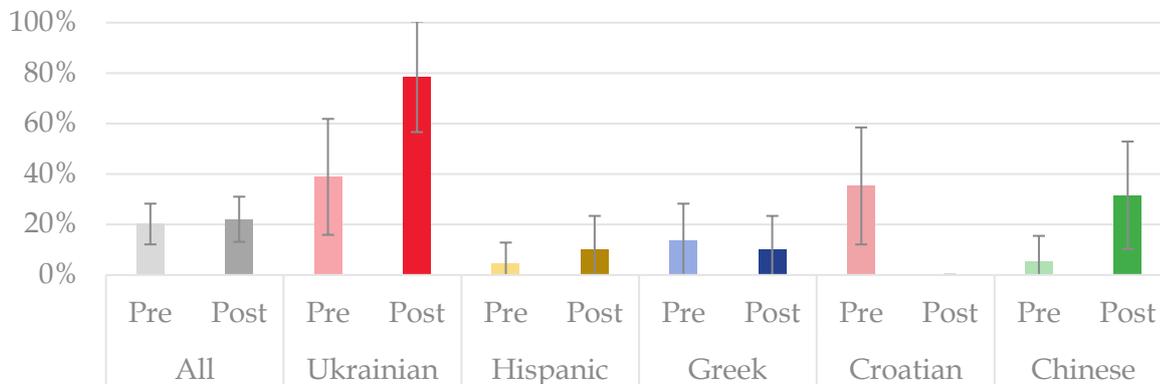


In general the use of computers to access information about services was not a common barrier, being endorsed by only 20.2% of all respondents pre-intervention. However, those in Ukrainian communities appeared to see this as a greater barrier, with 38.9% endorsement pre-intervention and 78.6% post-intervention. Cultural barriers and beliefs were perceived as an issue for 27.3% of respondents pre-intervention, although this appeared to be substantially less of a concern for those in the Hispanic community than others. Shame or stigma were not

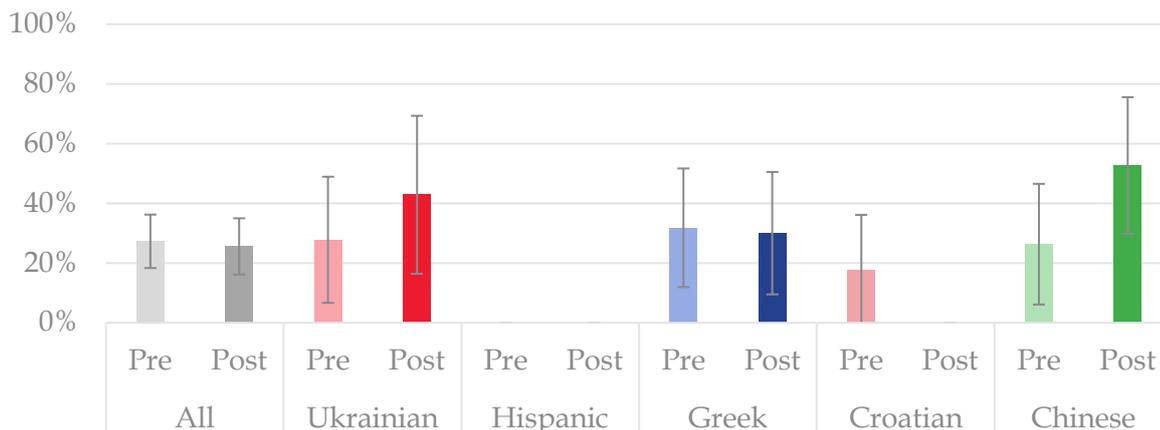
³² $\chi^2(1) = 13.65, p < .001$

considered to be a barrier to accessing services by the vast majority of respondents, and only 13.1% endorsed this barrier prior to the intervention.

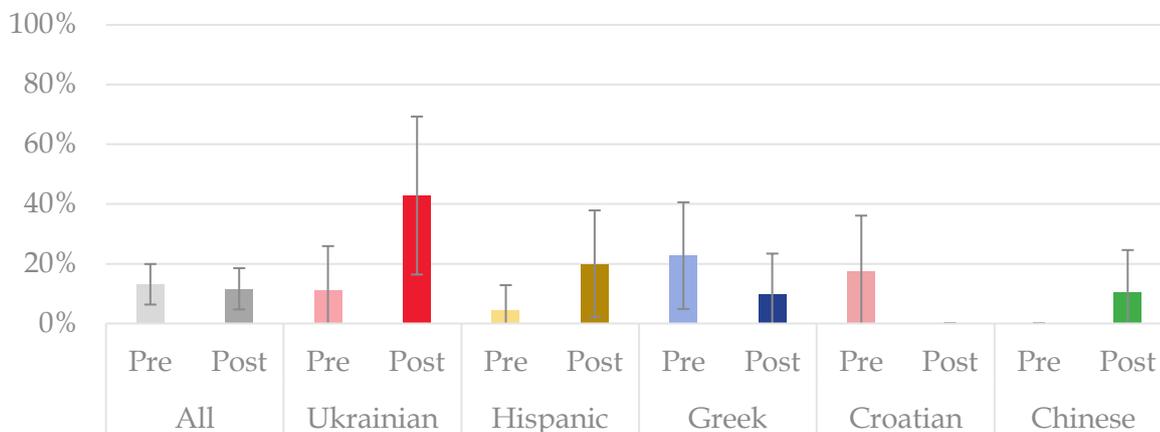
Barrier to accessing services: Hard to use a computer to get information



Barrier to accessing services: Cultural barriers and beliefs



Barrier to accessing services: Shame or stigma

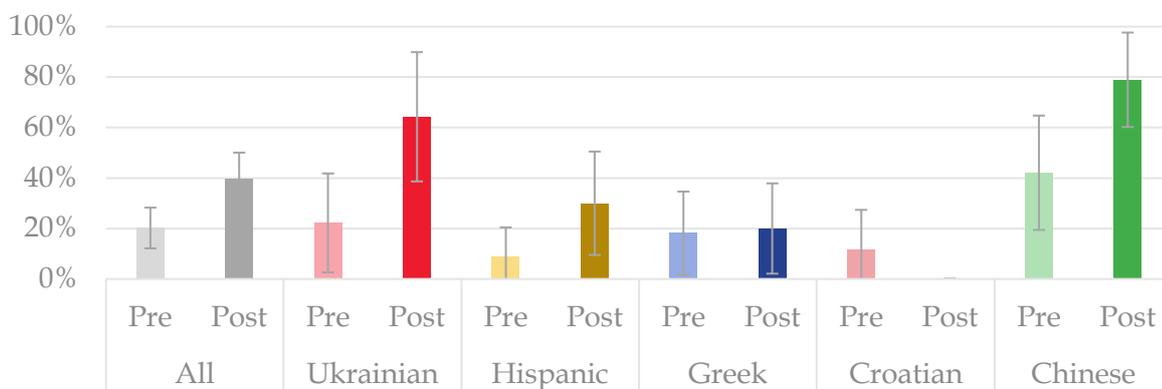


Spiritual and cultural needs regarding death and dying

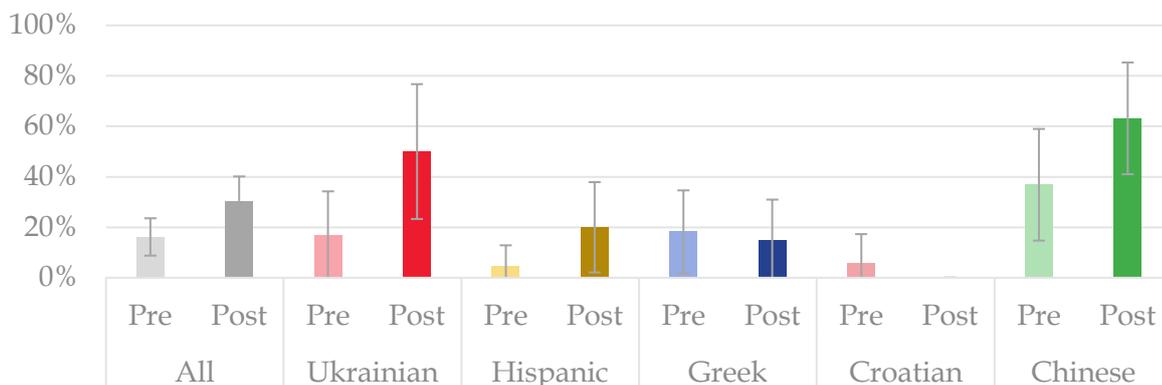
The proportion of respondents expressing a spiritual need regarding death that was not known or respected in broader society increased from a baseline of 20.2% to 39.5% post-intervention, a statistically significant change.³³ The proportion expressing spiritual needs differed significantly between communities post-intervention,³⁴ with Ukrainian (64.3%) and Chinese (78.9%) groups expressing a high level of spiritual needs relative to other groups (all $\leq 30\%$).

A similar pattern across time and between groups was observed for cultural needs regarding death not known or respected in society. Cultural needs increased significantly from a baseline of 16.2% to 30.2% post-intervention.³⁵ The proportion expressing cultural needs differed significantly between communities post-intervention,³⁶ with Ukrainian (50.0%) and Chinese (63.2%) groups again having a higher level of needs than other groups (all $\leq 20\%$).

Have spiritual need regarding death not known or respected in society



Have cultural need regarding death not known or respected in society



³³ $\chi^2(1) = 6.73, p = .009$

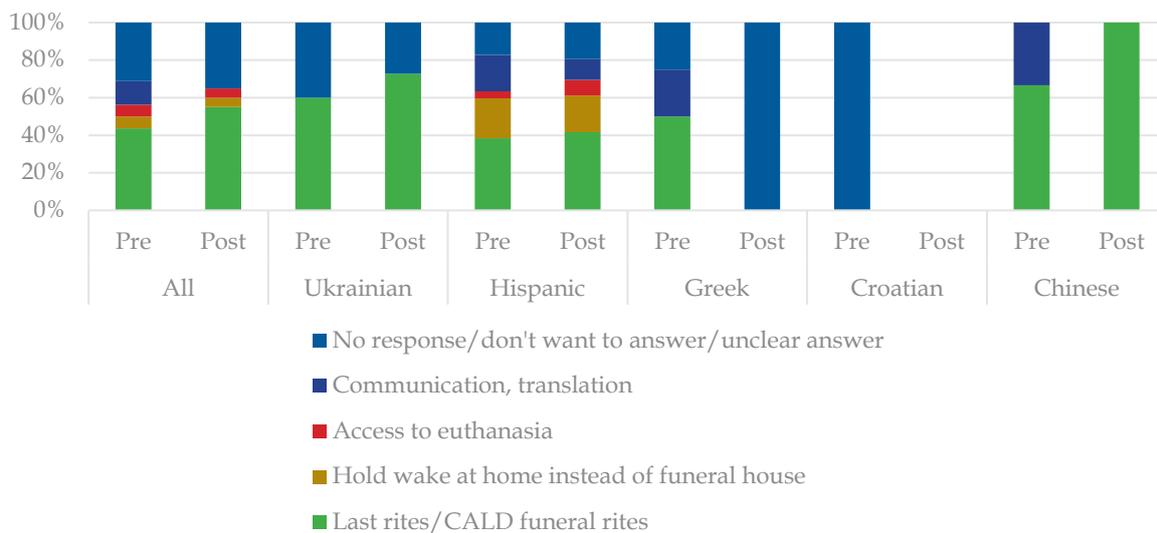
³⁴ $\chi^2(3) = 26.14, p < .001$; Hispanic group excluded due to only containing a single response

³⁵ $\chi^2(1) = 4.68, p = .031$

³⁶ $\chi^2(4) = 30.31, p < .001$

The most common cultural or spiritual needs regarding death and dying that were expressed by respondents were last rites or CALD funeral rites. Communication or translation requirements were expressed by some respondents from Hispanic, Greek, and Chinese communities. Respondents from Hispanic communities had needs for access to euthanasia and the ability to hold a wake at home instead of in a funeral house. These results should be interpreted with caution due to the small number of respondents, which limits the meaningful use of inferential statistics.

Cultural or spiritual needs regarding death and dying



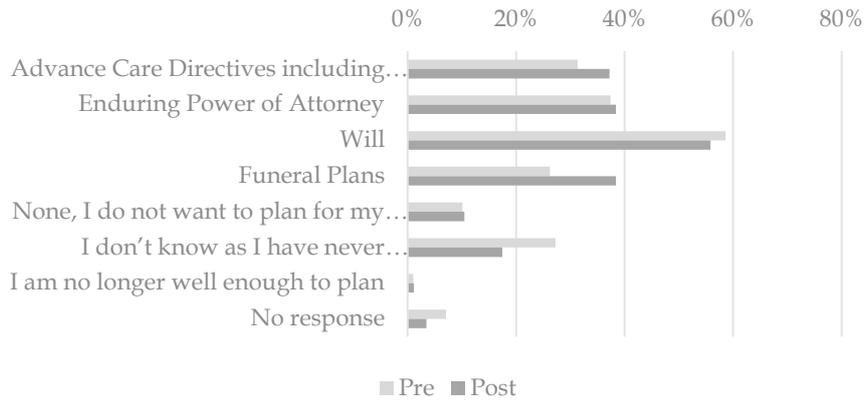
Plans made for death

Respondents were asked to state any plans they had made ahead of their own death. Pre-intervention, the most common plans were a Will (58.6% of respondents), Enduring Power of Attorney (37.4%), Advance Care Directives (31.3%), and funeral plans (26.3%). Over a quarter of respondents (27.3%) stated that they had no plans because they had never thought about it, while around one in ten (10.1%) indicated they preferred not to make plans for death. A small minority (1.0%) stated that they were no longer well enough to plan.

The proportion of participants indicating they had made funeral plans was 12.1% higher following the intervention, while the proportion reporting having never thought about plans for death was 9.9% lower. However, these differences were not statistically significant.³⁷ There were only minor differences in the rate of other plans for death before and after the intervention. Statistical comparisons between cultural groups could not be made due to the low number of responses.

³⁷ $\chi^2(1) = 3.11, p = .078; \chi^2(1) = 2.53, p = .111$

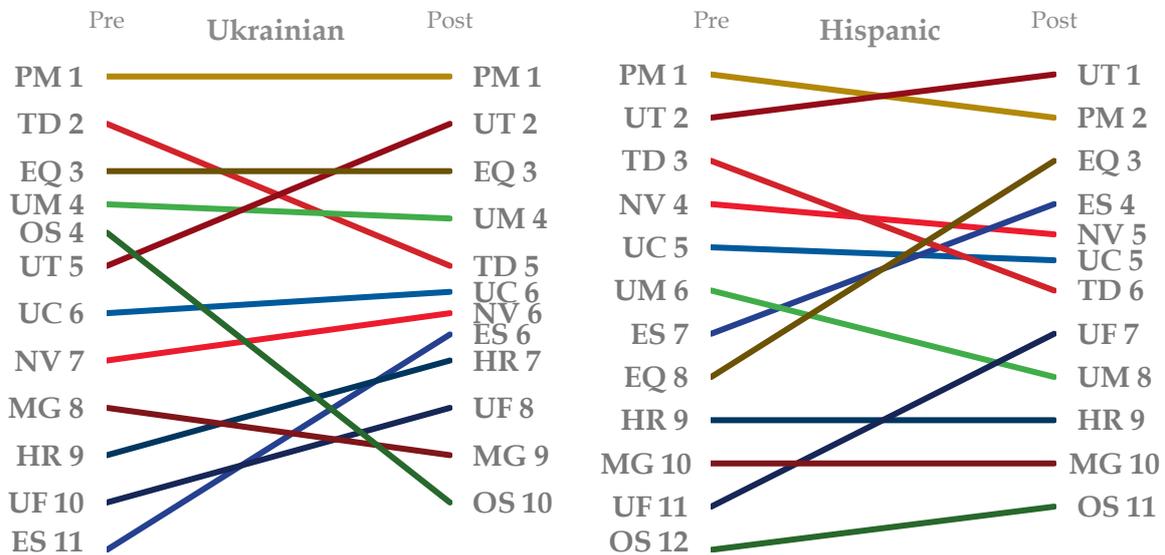
Plans made for own death

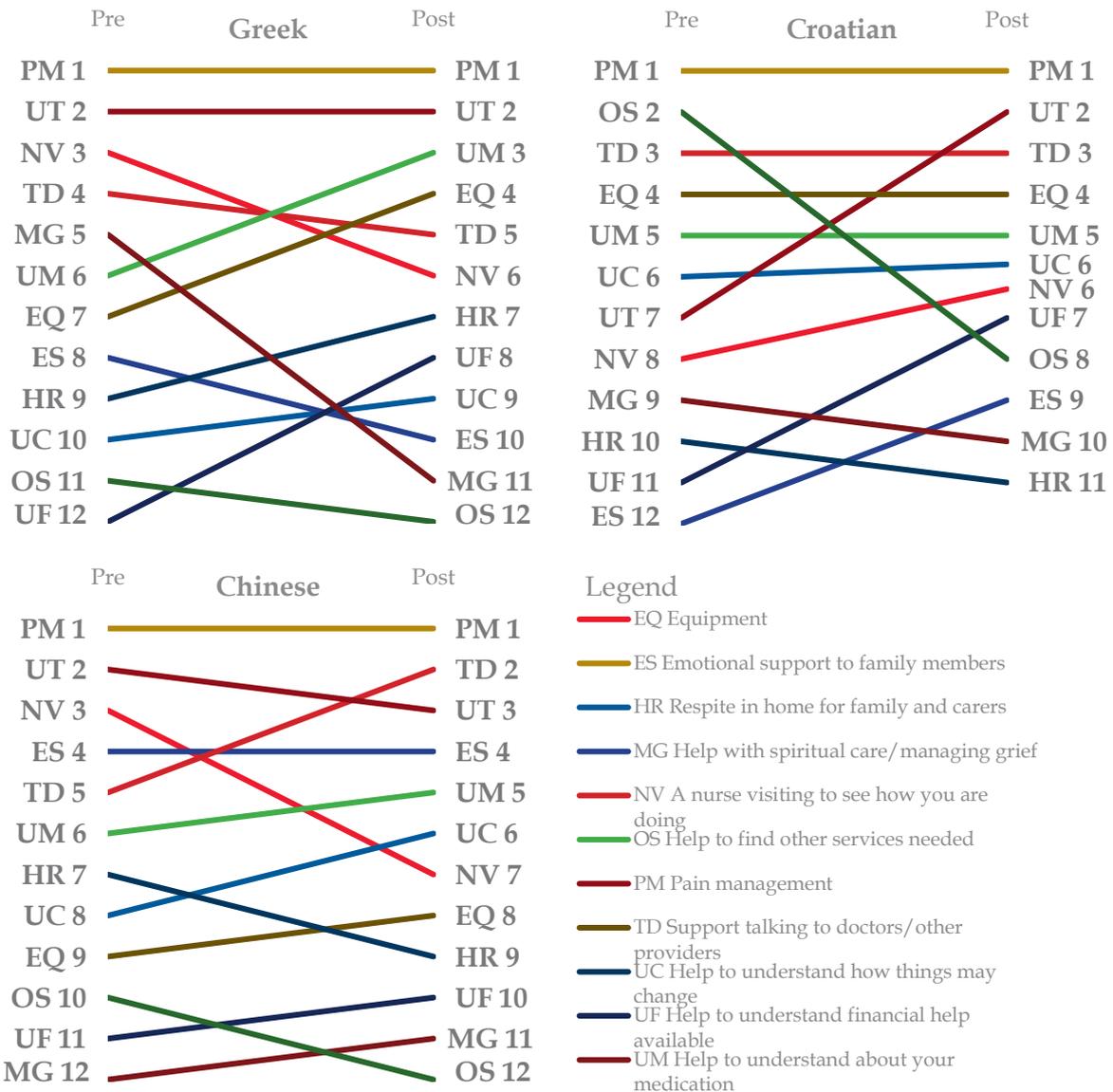


Importance of selected services to assist someone dying

Respondents were asked to rank a number of services in terms of their importance in assisting someone who was dying. Pre-intervention, the most important services across community groups was *pain management*, and this remained the case for all groups except the Hispanic community, where it dropped to second place, after *help to understand treatment options*. Other highly ranked services included support to talk to doctors and other treatment providers, help to understand options for treatment, and nurse visits. Differences in ranking after the intervention appeared substantial within some community groups, but there were few consistent differences between community groups, and availability of group ranking only, limiting the inferences that can be drawn from this data.

Importance of selected services to assist someone dying





Focus Group Results

Analysis focused on the identification of common themes in participant responses, informed by project objectives.

Community awareness of project activities

All groups were able to name activities within their community that focused on death, dying, or ACDs. Interestingly, whilst some of these activities directly linked to the project, others did not: some named developments within the wider community (e.g., the final report from Royal Commission into Aged Care Quality and Safety), or other community-directed information sessions focusing on health (e.g., on dementia, making a Will, or Power of Attorney) which prompted discussions about the relevance of ACDs.

Common points raised across groups were

a) the importance of ensuring that the form, nature, and/or timing of information circulated was tailored to meet community characteristics. That is, communication needed to be achieved via a medium (or media) that was accessible to and accessed by community members.

It depends on how you present it, you have to know your own cultural group and what's important to your people, on how and what you will present.

You have to know your people, your culture, the way they think and what's important to them.

For some, electronic media such as radio, podcasts, or social media were deemed successful; for others, dissemination via community newsletters or newspapers; some, however, stressed that successful communication required a face-to-face component, whether that was via small group discussion or one-on-one discussions with a community health-worker or leader. Similarly, one community mentioned that talk on death and dying was culturally inappropriate at specific times of the year, and any circulation or sharing of information that referenced such topics should be avoided during those times.

b) recognition that particular sectors of each community were more difficult to reach than others. For some, older people were noted as being somewhat isolated and unable to access or understand information provided; barriers included literacy, including health and electronic literacy. Others noted that younger persons were too busy or not sufficiently motivated to engage with the topic, either with parents or independently. Finally, some noted that language-based communities were not homogenous, that is, there were significant differences in how individuals or groups socialised or communicated, and therefore additional efforts were required to reach across communities that might be united by language, but little else.

c) some concern about reliance on a small number (i.e., in some, only one person) of individuals to lead or be a resource/contact person for information about these sensitive topics. All alluded to the importance of trust in that individual both to understand and respect cultural sensitivities as well as to either have relevant information or know how to access it (i.e., refer on to appropriate agencies).

Knowledge about palliative care

To prompt conversation about palliative care, participants were presented with a hypothetical case of a community member who was struggling to care for a family member as they approached the end of life, and asked if and how they would tell them about palliative care support. This was identified as the most sensitive topic to raise within community, partly because the concept itself was unfamiliar, with no direct translation into their language of origin. However, most noted that to raise the topic would require either implicit or explicit recognition that a) the individual was dying and b) the family was, to some extent, identified as limited in their ability to provide the care required and/or to manage the inevitable complex emotions present. Managing this required high levels of personal and cultural familiarity, and a high degree of trust in the person assisting.

In [language] we don't have an exact translation, so 'palliative care' is a strange word, so I need to use it to make it more familiar. I even looked it up in our dictionary, but no.

It depends who you are speaking to. You gauge them. Do I have to come in sideways or be direct? If they come to me for advice or help it's easier; I'd need to think if they are spiritual, or secular, or just frightened. I'd refer them to someone they trusted.

People would say thanks, but I don't know if they will act because they don't believe someone will die.

If they ask I'll tell them, otherwise I would never suggest this. It has to be their own choice.

It needs to be someone they trust, [because] we will need help with emotions then. We need more stuff about helping family to cope with grieving and anger, we need support especially if feelings vary within the family.

When asked, all groups were able to identify who or where to go (or refer someone to) for information about, or access to palliative care support. These included those named as involved in the current project including PCSA, MCCSA, and the community groups that had facilitated the project. Not infrequently, this latter included specific trusted senior member/s of their community (with some concerns about predicted loss of knowledge and access to services when those individuals stepped down). However, some communities also named medical individuals or institutions, allied healthcare workers, and religious individuals or institutions.

Finally, for some groups, the level of sensitivity regarding palliative care meant that even public discussion via community events addressing this needed to be managed indirectly, rather than directly, lest people simply avoid attendance.

You don't talk about palliative care, they don't want to hear about that, it is touchy, but they do want to know about Advance Care Directives.

Knowledge about Advance Care Directives

Most communities had previously expressed their familiarity with the purpose of a Will and that it was not uncommon for community members to have completed one, but indicated that they were not sure what additional end-of-life planning might be useful, or that there was some confusion about difference between a Will and an Advance Care Directive. Therefore, they were asked to identify the difference between these processes/documents.

Overall, there was a good awareness of the difference between purpose of a Will and ACD, but often confusion between the processes involved, as well as with other end-of-life processes / documentation such as Power of Attorney, Enduring Power of Guardianship, and Funeral Plans. Although there was some passing acknowledgement that young people might become incapacitated or unable to voice their healthcare preferences (typically due to accident), ACD was most commonly understood to be relevant to older persons (typically parents) approaching the end-of-life.

Will is for after funeral; the ACD is how I want to be treated and what is to happen to me at the end of my life.

The Will is what I want after death, my ACD is a like a will while I'm still alive; like a medical will which might make it easier.

The ACD is 'If you get sick, we need to know what you want to do; if you can't speak for yourself, what do you want, or who do you want to decide?'

Will is regarding the finance, and the ACD is regarding my health.

What's important to you, you put it in ACD, and the Will is after you pass.

The below table provides some observed points of distinction between a Will and ACDs.

	Will	ACD
Covers the time period ...	After my death	At the end of my life
About ...	My things/assets	My body/me
For ...	My family and friends	Medical professionals
The witness will ...	Not know what is in it	Know what is in it

There was a consistent and correct understanding that an ACD

- is intended to capture an individual's wishes and preferences for end-of-life care, and that it could be independently completed by that individual
- allowed individuals to name others (typically family) who could know what they wanted and could speak for them
- should be available to direct medical professionals (e.g., doctors, in hospitals and residential aged care facilities) in the event of a health crisis; and,
- that others (typically family) should be aware of the existence, content, and location of a completed ACD

However, some communities held beliefs that were somewhat incorrect, namely that

- an ACD could not be 'contested' unlike a Will
- a Will had to be completed by a lawyer, whereas an ACD did not
- a Will is legally binding whereas an ACD is not

Benefits of completing an ACD

Despite some points of confusion as noted above, there was high levels of awareness of the value of having conversations about death and dying, of planning for the end of life, and completing an ACD.

I can put down what I don't want to have if I am unconscious, I don't want to keep my life on, I don't want to be on a tube. Just let me go. I can put down I want to donate my organs to someone else. If I'm that age and I'm not well, I don't want to use up resources, I would waste resources and be a burden. I want to save some resources for others.

It's so you don't burden your children, you don't want to leave that decision to them, that's heartbreaking. It might be hard to talk about now, but it will be even harder then. If it's written down, it is peace of mind for everybody. Because you're grieving as it is.

If having it written, when I was best ready to talk in a non-emotional way this is what I wanted, and this is who I wanted to speak for me.

You can say things in ACD that are important culturally and religiously. Like I want to be visited by a priest, I prefer not to go to nursing home.

Across focus groups, participants agreed that ACDs benefited the individual through the opportunity to:

- state and help you ‘get what you want’ for your medical care
- to say things that are culturally, religiously, and personally important to you about how you want to be treated and cared for
- state what you didn’t want in medical care, typically, not to be kept unconscious on a tube

In addition, participants consistently noted benefits to others, most typically family, through providing a clear direction about the individual’s wishes for end-of-life care, thereby

- minimising confusion and disagreement within a family about what to do
- reducing the emotional burden of decision-making upon the family at a difficult and emotional time
- giving peace of mind to all
- minimising undesirable use of hospital resources, allowing these to be used by others

Some also noted that ambulance officers and admission processes currently asked about ACDs, so it was helpful to have knowledge of these beforehand, even without their completion.

Barriers to completing an ACD

Despite awareness of the above benefits, and acknowledgement of their own increased knowledge of ACDs, few (1-2 per group) had spoken with family about their preferences, and fewer (0-1) had completed an ACD—and always for a parent, never themselves. Reasons for this included personal or cultural beliefs, perceived lack of relevance, and practical impediments such as limited access to resources, or the complexities involved in completing the ACD. All noted the importance of ensuring that information was not only available in their language, but was available in ‘lay persons’ rather than ‘medical’ language. Some, however, observed that an effective translation from lay to medical language could be useful in some medical settings, ensuring that healthcare professionals were clear about an individual’s preferences. Some communities noted cultural understandings that talk about death was taboo, that dying or terminally ill patients should not be informed of their prognosis, that family would know and be trusted to follow shared cultural traditions, and that these factors impeded conversations about planning for the end of life.

[Our] people don’t want to talk about death, so you don’t want to do these things even if have a thought [you should]. Maybe some people know we have to do when healthy, but most people only will do it when they really need to go to hospital and they think ‘this is maybe the time I need to do something.’

The language is a problem. ... the [What matters most] cards [with both languages on] really helps us, even in English because I need to know the terminology in English. Even if you give us the ACD form, if someone doesn’t explain, really explain in [language], what it is all about, we just cannot follow. I can talk in English, I can understand when I say it to you, but not always read or write. I need help and we’ll do it together.

We commented so many times that the [What matters most] cards [with both languages on] really helps us, even in English because I need to know the terminology in English.

With our faith we would do the right thing which is what the parent wants. You follow the tradition, which means, the parent doesn’t want to make a decision, because they know the children will do the right thing.

Younger people don’t think it applies to them, or they don’t want to acknowledge that it applies to their family. So they minimise the seriousness of symptoms that say do it now (like dementia).

Poor people, the workers, we don’t do this. Only the rich. This is not for me.

People are scared. It’s about dying and if we do it, we might die. People are fearful that if I make it, it means I am dying. If someone recommends it, it means I’m dying.

We think it is not lucky to talk about death, it then the bad things will come. Some people don't want to have a Will, because that is a bad thing. It is tradition and culture.

I have three kids and they have Power of Attorney, and I don't need any other paper, because my kids know how I like it, what has to be done, I have my faith and that will direct it.

Whilst affirming their own increased comfort with discussing death and dying, all agreed that the topic was confronting, requiring the 'right moment' for discussion, and the process was time-consuming to complete. Some noted that family already knew their wishes, sometimes because of well-understood cultural norms and practices surrounding death and dying. Other barriers suggested were that

- family (i.e., adult children) were reluctant discuss the possible death of their relative and dismissed attempts by an individual to raise the topic
- family were too busy to learn more about and help an older individual to complete the ACD
- end-of-life planning was foreign to many, in that cultural norms and practices in their country of origin did not include notions of choice, sometimes being something only 'rich' people did; for some, what happened at the end of life was in the hands of fate or God
- opening a conversation about death was tempting fate or inviting bad luck, or as a signal that someone involved was dying
- some expressed concerns that writing down their wishes might
- circulation in media or community about negative stories featuring an unwillingness of healthcare professionals to seek, acknowledge, or attend to cultural or personal preferences as expressed by individuals in an ACD or via family (sometimes named as Substitute Decision-Makers)

More pragmatically, some noted that they "hadn't gotten around to it because I'm young' notwithstanding acknowledgement that death could happen at any age; some commented on the difficulty of naming a Substitute Decision-Maker, particularly where they had more than three children, or where one or more of those were interstate or overseas.

What was the key message you got from these activities?

The key message for the participants was that, although conversations about death and dying were difficult, they were important and useful, and, there were resources available to help. Most noted that, whilst they had not done anything specific to share their preferences for end of life care, they felt more comfortable with the topic, and could envision that they might, at some point, initiate conversations with family so they were aware of their preferences. Most expressed positive views that the Advance Care Directive gave them the opportunity to ensure that others knew and would work to act on their preferences; and, that it was something they could do by themselves. Several expressed appreciation that the project was centred around their community needs, that communities had their own networks within and knowledge of the needs and preferences of their members, and how essential this was to successful communication of these messages.

Sometimes I have things don't want to say to anyone, but I can put in the ACD, like a special song I want and to go to the people who love me – I can write that down and put it in. So the main point is I can make it how I want to be.

It is important to say what you want so you don't get what you don't want.

I know that this is available, and I don't have to go to a lawyer, I can do it myself

It helps focus conversations to before we die, not just after when we are dead. I wasn't talking about death before, but now I'm comfortable talking on it.

We have a community network ... so we can and do piggy-back onto other things because we have a network we can use. We do need the funding to help us to spread any message. We need support because we are volunteering. And, we need to build on this momentum, though we need not to overload. So do a burst and break, then a burst. We know how to do that because of our networks, we can coordinate because we know our community. It's culture culture culture. Palliative care is not just about end-of-life and death; we need to change to the belief that it is helping with long-term goals and you.

What is needed to continue to promote Courageous Conversations within CALD communities?

Overall, there was clear recognition that the project had been successful in increasing attendee awareness of the value of discussions about death, dying, and the value of end-of-life planning.

- All groups additionally noted that further such efforts and activities were required to build upon the increased awareness of and willingness to engage with these difficult concepts, and that without these, people were unlikely to convert awareness to action.
- Many noted that they represent a unique cohort within their community who were willing and able to be involved in the project activities, and that there are significant sectors who, for various reasons were not.
- All noted the need for resourcing to support these activities, many noting a reliance on one or a few trusted individuals within the community.
- All stressed that any communication about these topics must be tailored to the cultural needs of their community as a whole, and account for differences within their community that influenced where and how to reach different demographics (e.g., differences in age, religion, social contacts, literacy).

Recommendations of ways to continue to promote increased community awareness of Palliative Care and ACDs as well as familiarity with and willingness to discuss death and dying (a necessary precursor to engagement with Palliative Care and ACDs) are listed below.

- Keep offering sessions on these topics: short and regular is optimal
- Provide funding to 'train the trainer,' that is upskill and fund appropriate individuals to facilitate conversations about and completion of ACDs
- Fund and offer information on a range of related topics (e.g., Wills, Power of Attorney, Funeral arrangements, Palliative Care, Advance Care Directives) and cross-reference within all of them, whilst allowing communities to select those of current interest and relevance. Don't overload by trying to cover too much at once.
- Provide culturally-based case studies or stories that feature the provision of palliative care that met individual, family, and cultural needs, and the making and benefits of Advance Care Directives to increase familiarity and relevance
- Allow additional time for community forums, especially where translation is needed, to enable more in-depth sharing of experiences and thoughts
- Use an adult education model of small group work to encourage feelings of safety and belonging in discussions; don't just lecture, allow time to discuss and reflect
- Make targeted efforts to include younger people, possibly including within primary, secondary, and tertiary education
- Provide information where and how people prefer to access information (what works for some will not work for all)
- Build on community interest in financial planning and topical news stories (e.g. on nursing homes, elder abuse) to insert mention of the benefits of ACD and palliative care
- Augment discussions with hardcopy resources and information about online links
- Provide and practice culturally acceptable strategies to introduce such conversations; the 'What matters most' cards were a good example of this.
- Help interested individuals move from conversation to completion of ACDs through practice sessions

Conclusion and Recommendations

The objectives of this stage of the project were met. Led by facilitators/leaders who attended the initial workshops, each community tailored and adapted the information provided to maximise reach and relevance, resulting in meaningful differences in pre-and post-intervention Knowledge, Attitudes, and Practices about death, dying, palliative care, and Advance Care Directives. Both MCCSA and PCSA facilitated this, providing resourcing and personnel time to support community activities. This outcome was significantly reliant on the trust and goodwill inherent in the extensive existing relationships and network between the individuals and organisations involved. In this MCCSA played a pivotal role in introducing and supporting communication and interactions, acting as a bridge between PCSA and the CALD community-based organisations.

Appendices

Appendix A: Community Training Workshop Program



MCCSA/PCSA Community Training Workshop Held at MCCSA on 1st September 2020 Program

- 10.00 a.m.** **Acknowledgement of Country**
Welcome / Introductions & Housekeeping (Helena Kyriazopolous, MCCSA)
Project Purpose & Outline
- 10.15 a.m.** **Talking about dying** (Mark Waters, PCSA)
- 11.15 a.m.** **Break**
- 11.30 a.m.** **Getting our houses in order**
- 12.45 a.m.** **Lunch**
- 1.15 p.m.** **What is Palliative Care?**
Where can services be accessed? A Life Well-Lived.
Delivering in the Community
- 2.30 p.m.** **Any last questions**
Evaluation (Jaklin Elliott, University of Adelaide)
- 3.00 p.m.** **Close**

Appendix B: Knowledge Attitudes Practice Survey

Courageous Conversations Knowledge Attitudes Practices survey (used pre- and post-intervention)

(SECTION 1)

1) Your Community

(Single choice)

- Chinese
- Croatian
- Greek
- Spanish Speaking
- Ukrainian

2) Your Gender

(Single choice)

- Male
- Female
- Other (please state) _____
- Prefer not to say

3) Your Age

(Single choice)

- 15 to 24
- 25 to 44
- 45 to 64
- 65 to 74
- Over 75

(SECTION 2)

4) What do you think palliative care is?

(Open question)

5) Which services do you know of that provide palliative care for people who are facing death?

(open question)

6) Please describe how your community supports those who are grieving.

(open question)

7) Do you know what an Advance Care Directive is?

(Single choice)

- Yes
- No

8) If yes please describe

(Open question)

9) Have you completed an Advance Care Directive?

(Single choice)

- Yes
- No

10) If no, why not?

(Open question)

11) Do other people know what care you might want if you became too unwell to say it yourself?

(single choice)

- Yes
- No

12) If yes, how do they know?

(Open question)

(SECTION 3)

13) How comfortable are you speaking about death and dying (where 1 indicate “not at all” and 5 “completely”):

(please circle)

- a. As an individual (1 2 3 4 5)
- b. Within your family (1 2 3 4 5)
- c. Within the wider community (1 2 3 4 5)

14) Have you ever spoken with someone about your or their thoughts about death and dying?

(Single choice)

- Yes
- No

15) If yes, who did you talk to?

(Open question)

16) In which way might you start to talk with your family about death and dying?

(open question)

17) What might stop you from speaking about death and dying?

(Open question)

(SECTION 4)

18) Have you ever gone through the death and dying process with someone before?

(Please choose all that apply)

- No never
- Yes for someone I cared for at home
- Yes for someone that was in hospital
- Yes for someone who was being cared for in another home

19) Would you ask for professional help or support in looking after someone close who had a terminal disease or was close to death?

(Multiple choices)

- Yes I would
- No I wouldn't

20) If yes (for q.19), who would you ask?

(Open question)

21) If yes (for q.19), what kind of assistance would you ask for?

(Multiple choices)

- Grief and potential loss management
- Spiritual guidance/support
- Treatments
- Financial or economic support
- Emotional support
- Access to equipment
- Pain management
- Other (please list)_____

22) If you answered "no" (for q.19), why is that?

(Multiple choices)

- I don't talk about these very personal things
- Only family members should take care of their elders/ill people
- Shame or stigma in the community
- I didn't know that services are available
- Other (please list)_____

23) Would you ask for professional help or support for yourself if you had a terminal disease or were close to death?

(Multiple choices)

- Yes I would
- No I wouldn't

24) If yes (for q. 23), who would you ask?

(Open question)

25) If yes (for q. 23), what kind of assistance would you ask for?

(Multiple choices)

- Grief and potential loss management
- Spiritual guidance/support
- Treatments
- Financial or economic support
- Emotional support
- Access to equipment
- Pain management
- Other (please list)_____

26) If you answered “no” (for q.19), why is that?

(Multiple choices)

- I don't talk about these very personal things
- Only family members should take care of their elders/ill people
- Shame or stigma in the community
- I didn't know that services are available
- Other (please list)_____

27) How important do you believe these services are to assist someone dying:(Indicate preferences from 1 to 12, where 1 is the most important and 12 the least important):

- ___ A nurse calling or visiting to see how you are doing
- ___ Pain management
- ___ Help to understand how some things may change (taste, memory, energy level)
- ___ Emotional support to family members
- ___ Support to talk to doctors and other help providers
- ___ Help to understand all about your medication
- ___ Help to understand your options for treatment
- ___ Equipment (hospital bed, shower chair, wheelchair...)
- ___ Respite in home for family and carers
- ___ Understand financial help available
- ___ Help to meet spiritual care needs and manage grief
- ___ Help to find other services you may need

28) What might get in the way of accessing services:

(multiple choices)

- Language barrier/ English is not my first language
- I don't know there are such services
- Hard to use a computer to get information
- Cultural barriers and beliefs
- Shame or stigma
- Other (please list) _____

29) Do you have any spiritual need regarding death and dying that you think is not known or respected in the society you live in?

(Single choice)

- Yes
- No

30) Do you have cultural needs regarding death and dying that you think are not known or respected in the society you live in?

(Single choice)

- Yes
- No

31) If you answered yes to question 28 or 29 please describe what it is you need?

(open question)

32) What plans have you made (or do you want to make) for your own death?

(Multiple choice)

- Advance Care Directives including Substitute Decision Maker(s)
- Enduring Power of Attorney
- Will
- Funeral plans
- None, I do not want to plan for my death
- I don't know as I have never thought about it
- I am no longer well enough to plan

Appendix C: Summary of all Community-led Awareness Campaign Activities

Chinese community activities

- 1- Two Cantonese forums on Palliative Care held October 13th (33 participants) and October 20th 2020 (38 participants).
- 2- Two Mandarin forums on Palliative Care held October 16th and October 23rd (28 participants).
- 3- Article on Newsletter to all members in 400 copies published 25th January and distributed via post
- 4- Article on Wechat CWS official Account, published 29th January. 300 people are linked to this platform
- 5- Article on Community newspaper, published 29th of January. The newspaper is published in more than 14,000 copies and distributed in MEL, SYD, BNE and Adelaide.
- 6- Information sessions to Chinese School of SA and Chinese School of CWS, starting January 30th.

Croatian community activities

- 1- Community Forum: -Radio Forum a dedicated radio program episode was broadcasted on December 16th. During the program people could ask questions; many people later called the office for more information, demonstrating good reach and high interest about the topic
- 2- Radio Podcasts: the six Radio Podcasts were circulated on the Croatian Radio Program on Radio 5 EBI for 5 weeks
- 3- Monthly Newsletter: to around 180 Croatian families. In the months of November, December, and January a Searchword game was created using all terminology from Palliative Care; the text of the podcasts will be published, one per Newsletter.

Greek community activities

- 1- Meeting and presentation with the Presidents of various Greek Communities, on October 19th. 26 Greek community leaders attended.
- 2- The Radio Podcasts in Greek uploaded on the GWC Facebook page during Christmas break
- 3- Poster, Flyers and Promotion. This activity was planned by the end of November when the 2 days total lockdown was enforced. The activity will restart at the beginning of 2021

Hispanic community activities

- 1- HWASA Palliative Care Forum
- 2- Poster and Facebook promotion
- 3- Personal Group presentations
- 4- Podcast
- 5- Webpage

Ukrainian community activities

- 1- Ukrainian Community Palliative Care forum on Thursday 22 October. 29 people attended.
- 2- Distribution of Palliative Care packs to our 80 CHSP clients (living at home) with explanation in Ukrainian language.
- 3- Article in the Community Newsletter distributed using the community e-mails contacts (approximately 200 families)
- 4- Posters and pamphlets distributed to community's 4 churches and community hall.
- 5- Information broadcasted on 5 EBI FM by Ukrainian Radio INC in one dedicated program in December 2020.
- 6- Podcast by MCCA on 5 EBI FM by Ukrainian Radio INC for 4 weeks.

Appendix D: Community Training Workshop Session Outline

Session 1 Talking About Dying

Purpose: -

- To start a conversation about death and dying
- To identify cultural enablers and barriers to holding such conversations
- To explore individual hopes and fears in relation to dying

Content: -

- Icebreaker
- Death & Taxes - slide
- What Matters Most – large group exercise
- AHA Report – Cultural Enablers and Barriers - slide
- Hopes and fears – large group discussion

Session 2 Getting our Houses in Order

Purpose: -

- To discuss the importance of planning earlier for end of life
- To provide information upon Advance Care Directives (ACDs)
- To provide resources re ACDs and Funeral Planning

Content: -

- Advance Care Directives – presentation / slides
- What Matters Most – Small Group Exercise - Cards
- Funeral Planning – Large Group Discussion / Booklet

Session 3 What is Palliative Care? Where can services be accessed? A Life Well-Lived. Delivering in the Community

Purpose: -

- To inform participants of the definition of Palliative Care
- To identify where and how Palliative Care Services can be accessed
- To provide resources upon Palliative Care
- To discuss the importance of memories and grief
- To gauge the need for further mentoring and supports from today

Content: -

Slide presentation

- What is Palliative Care? – WHO Definition –
- Where are the Services Available? –
- Integrated Model of Care
- What Happens As We Die? –article from the Age Newspaper
- What resources are available to support more learning?
- How do you want to be remembered? – Large Group Discussion
- Community Engagement – Next steps Discussion
- Questions

Appendix E: Participant Workshop Evaluation Form



FEEDBACK FORM FOR COURAGEOUS CONVERSATIONS WORKSHOP

Thank you for joining us in this conversation today. We invite your feedback which we will use to improve how we approach these conversations in the future. The findings from this feedback will be provided in a report to our funding body but we will summarise information and not identify individual responses.

There are three parts to this feedback form: A). About you; B). About the organisation of this workshop; C). About your views on the discussion today.

A. About you

1. What is your community? (please check one)

- Chinese
- Croatian
- Greek
- Spanish speaking/Latin American background
- Ukrainian

2. What is your gender? (please check one)

- Female
- Male
- Prefer not to say
- Other (please indicate) _____

3. What is your age (please check one)

- 15-24
- 25-34
- 35-44
- 55-34
- 55-64
- 65-74
- Over 75

4. What is your role within your community? For example, religious leader, elder, community worker, community member, volunteer, other (please indicate)

5. Have you provided support to someone at the end of their life?

- No
 - Yes, as a family member
 - Yes, as a friend
 - Yes, as part of my role in community
 - Yes, in another role (please state which role/s)
-

B. About the organisation of this workshop

1. Please indicate the extent to which you agree with these statements about this workshop

Statement	Not at all	Partly	Fully
The information presented will help me educate my community about these issues			
The information provided was clear and easy to understand			
The facilitator was knowledgeable and well prepared			
I felt comfortable asking questions			
Any questions were answered well			
The event was well organised			

2. What could we do to improve future workshops on these issues?

C. About your views on the discussions today

1. This workshop ...

Statement	Not at all	Partly	Fully
... provided a safe space to talk about death and dying			
... helped develop my understanding about new information			
... helped me develop new skills that will be useful			

2. After this workshop I feel confident that I ...

Topic	Not at all	Partly	Fully
... can identify and help my community to overcome barriers to talking about death and dying			
... could open a discussion in my community about death and dying			
... can simply and clearly describe what palliative care is			
... know where to get more information about palliative care			
... know what an Advance Care Directive (ACD) is			
... know the benefits of completing an ACD			
... can identify some barriers to completing an ACD			
... know where to find information or resources about ACDs			

3. What things were most helpful to you personally in this workshop?

- a)
- b)
- c)

4. From today's workshop, what things will help you the most to assist your community?

a)

b)

c)

5. Are there any topics about which you feel you need more information from MCCSA and PCSA before you hold your community forums?

a)

b)

c)

6. What do you think will be your biggest challenges in talking with your community about death and dying?

a)

b)

c)

7. What would help your community members to have conversations about death and dying?

a)

b)

c)

8. What things would best help people in your community to have conversations about planning for the end of life?

a)

b)

c)

9. What things would best help people in your community to complete an Advance Care Directive?

a)

b)

c)

10. Is there anything else you would like to add?

.....

.....

.....

.....

Thank you for participating in this workshop and completing this feedback form.

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