



PalliativeCare
WESTERN AUSTRALIA



Curtin University

Evaluation of PCWA Advance Care Planning Workshops (Summary Report)

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Introduction

Palliative Care Western Australia (PCWA) are running workshops in local communities around WA on Advance Care Planning (ACP) in order to improve knowledge and understanding of ACP and its components, and to increase the uptake of ACP.

The workshops focus on people having a conversation with family, friends, health professionals or other professionals about end-of-life wishes, and aim to encourage the completion of ACP documentation. Curtin University conducted an evaluation of the WA ACP workshops in terms of content but also, importantly, to ascertain if the workshops increase knowledge and change behaviour.

ACP has demonstrated significant and multiple beneficial outcomes for patients, particularly those with a serious chronic or life limiting illness; families; and for the health system as a whole. For example, undertaking ACP can improve patient and family satisfaction with end-of-life (EoL) care, increase access to more appropriate palliative care, reduce undesired invasive and futile treatments, reduce stress, anxiety and depression experienced by families, and may also reduce net health expenditures.

Approximately 82% of people believe that it is important to discuss their EoL care preferences but only approximately 14% of Australians nationally and 8% in WA have completed an ACP or AHD. People over 65 years are more likely to complete ACP documentation if they reside in a residential aged care facility or are admitted to hospital; people living in the community seeing a GP are less likely to complete such documentation. Research shows that approximately one in two people will not be capable of making their own medical decisions at EoL, most Australians will die from a chronic illness and a third of Australians will die before age 75 years. As such, there is an urgent imperative to increase the percentage of Western Australians completing an ACP or AHD, and increase the numbers of people discussing their EoL care preferences, especially in the community.

Evaluation

We evaluated changes in behaviour and knowledge related to end-of-life planning after WA community ACP workshops. The overarching aim was to examine if WA ACP workshops changed knowledge and behaviour in relation to end-of-life planning. Specifically, if the ACP workshops changed behaviour in relation to conversations about end-of-life wishes; if the workshops changed behaviour in relation to completion of end-of-life planning documentation; and if the ACP workshops changed knowledge in relation to ACP. We used surveys and in-depth, individual qualitative interviews.

Participants were recruited from a sample of consumers who attended a community ACP workshop in WA during 2018 and 2019.

Participants completed surveys at 3 time points:

Time 1

The *pre-workshop* survey asked for demographic information, assessed participants' prior knowledge and experience with ACP, their goals, motivation for attending and their expectations.

Time 2

The *post-workshop* survey asked participants whether their expectations were met, how they felt about the content and delivery, and what they planned to do following the workshop (in terms of ACP).

Time 3

The *follow-up* survey assessed participants' conversations with others regarding ACP, as well as completion of ACP documentation. Time 3 follow-up surveys were mainly completed online; participants were sent a link (3-6 months following the workshop) to a website via an automatic text message or e-mail. People who did not respond were followed-up by telephone and those who were unable to complete the survey online were given the option of completing the survey via telephone with a research assistant, or were sent a paper copy to return via mail.

Interviews were also completed:

Nine workshop participants were individually interviewed regarding their motivation for attending the workshops, wishes for end-of-life care, their values and goals, and their thoughts about the workshops. Gaps and challenges were also discussed, including what worked and did not work, and any suggestions for changes.

Our focus was on changes from Time 1 to Time 3. Time 2 was an evaluation of the workshops, the results of which we have previously reported (see Interim Report, May 2019).

Findings and Discussion

As far as we are aware, this is the first study examining whether ACP education in the general community leads to changes in knowledge and behaviour (conversations about end-of-life wishes and completing documentation). Below results are summarised for each time point then a conclusion is provided. The most powerful evidence for the effectiveness of the workshops is in ***bold italics***.

Time 1

The findings revealed that most people who attended the workshops had thought about their preferences for types of care and treatment. This reflects stage 2 of the behavioural change model where people are thinking about changing behaviour. People who had such a conversation revealed they had talked to family members rather than health professionals, including GPs, about their end-of-life wishes. This is important as we can take a two-pronged approach in the future; continuing community workshops but also working with GPs and other health professionals.

The main reasons for not having a conversation were that people did not have the knowledge and did not feel ready or prepared. Time, confidence and willingness of other people to discuss ACP were not as salient.

Most people were aware of the legal documentation but fewer people were aware of Advance Care Plans and Advance Health Directives, with an even split between people who were aware and those not aware of these latter health documents. Most people felt that their end-of-life plans were not adequate. Our conclusion is that we need to move people from contemplation to action.

Time 3

The strongest evidence for the success of the workshops in increasing knowledge and changing behaviour came from our statistical analyses. Simply stated, and bearing in mind we did not have a control group, findings indicated that the WA ACP workshops lead to statistically significant changes in knowledge and behaviours related to ACP. Namely, thinking about preferences and wishes for EOL; viewing EOL plans as adequate; number of conversations with others about EOL wishes; and understanding of key concepts related to ACP. These are powerful findings and indicate that the ACP workshops make a difference to people who attend in terms of ACP knowledge and behaviour.

The descriptive statistics showed an increase in the number of people having conversations with family members but there were fewer people having conversations with health professionals. All these conversations were rated highly in terms of usefulness. Most participants explicitly stated the workshops had prompted these conversations. Interestingly, the main reasons for *not* having a conversation had changed from time 1 to time 3, and not feeling ready and not finding the right time were the main reasons (though numbers were low for both). This suggests that the workshop had met the needs of those who had little knowledge, lacked confidence or did not feel prepared. This is a salient finding, which is worth noting. The workshops appeared to meet the needs of people who want knowledge, want to feel confident and want to be prepared before acting (changing behaviour).

Many people had completed documentation but we need to highlight that some were still thinking about action. Given the power of the workshops to change behaviour and increase knowledge, follow up workshops would be a good investment. Storage of documentation was usually at the family home or with family members. A session on reasons for using My Health Record or a WA Register could be useful in future workshops. The workshops prompted many people to complete documentation, a further argument for continuation of the workshops. People, in general, wanted help in completing the documentation mainly from further workshops or their GP, and this support needs to be free or low cost. A few participants had difficulties accessing My Health Record and also reported that their GP and other medical professionals did not know what to do.

Conversely, there was no change in behaviour related to registering as an organ donor, which could suggest that this is a different concept, is not of interest or that people have already changed their behaviour in relation to this issue. As such, this topic could be removed from the workshop.

Interviews

Motivation for attending

Motivation for attending the workshop included being up to date on the issues; having the 'right' words; not wanting to leave everything to others; and to get an understanding of what was needed. The workshops met these expectations and provided knowledge. The concept of having the 'correct' words was a recurring theme and something future workshops could include. Specific examples were also clearly needed. Most participants want to get things sorted so that they can have their say regarding their EoL wishes and so they are not a burden to others.

End-of-life wishes

Most participants were clear about their wishes for EoL care and did not want invasive life extending treatments that would destroy their independence and quality of life. Also, most participants would prefer to stay at home as long as possible. However, some participants hoped that they would not need to do such planning, many thought they would deal with issues when the time comes, a few believed that someone else would be around to deal with decisions and know what to do, and a few people thought that they are too young to do anything yet. The workshops helped people to think about their own wishes and values and resulted in feelings of confidence, especially in starting conversations about EoL wishes. Participants also expressed a feeling of being more in control over their future.

Challenges

Some participants were worried about their wishes being followed by doctors. Concerningly, many people encountered reluctance when they raised the conversation with friends, their GP or solicitor. We also need to think about, and plan for, people who live alone with no family or friends, as participants without close relatives and little finances/resources struggled to know who to appoint as their EPA or EPG. Participants stressed that not all GPs were knowledgeable or willing to discuss EoL issues, and many participants thought that it would be difficult for the GP to initiate the topic.

Conclusion

In summary, the workshops were *highly* effective for this group of participants. We know from previous evaluations that the workshops are considered useful, but we now have very powerful evidence that they are successful in meeting the aims of WA ACP workshops, namely changing knowledge and behaviour in relation to ACP.

Recommendations

- Continue to roll out ACP workshops across the WA community.
The evaluation has provided substantial evidence for the effectiveness of the ACP workshops in effecting behavioural changes i.e having a conversation with others about end-of-life wishes and completing documentation. Consideration might also be given to offering a train the trainer program to facilitate other organisations to implement this approach.
- Develop ACP workshops and/or materials for GPs.
Most people have a conversation about end of life wishes with family members rather than GPs. This could be because GPs do not ask. Many people would like GPs to help them to complete ACP documentation.
- Modify workshops to remove discussion of organ donation.
There was no change in this area so we can conclude that ACP workshops do not lead to a change in consideration regarding organ donation.

- Emphasise the benefits of lodging documents with My Health Record or a WA Register if the WA State Government proceeds with the Joint Select Committee on End-of-Life Choices' recommendation on this, and educate GPs and hospital staff.
Most people keep their documents at home or with family members.
- Explore the development of follow up workshops and/or templates to help people complete documentation.
Many people wanted follow-up workshops and help completing documentation and finding the 'right' words.
- We need to consider workshops for vulnerable groups including people who live alone with no family or friends, people living in supported accommodation such as homeless shelters, and people with mental health issues.
- Future research should look at a follow-up survey at around a year after the ACP workshop to see if people maintain behavioural changes and if people reflect on their decisions and end-of-life wishes.
The WA ACP workshops move people from contemplation of ACP to ACP action. However, the final stage of the behavioural change model - maintenance and reflection - was not explored.
- Future research should look at using a matched control group.

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