

## 1.1 Awareness of ACP

O01

### **Volunteer-led advance care planning advisory and education services: An evaluation of a new model for Australian service delivery**

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**Background:** Research on utilising volunteers in advance care planning (ACP) is limited. Advance Care Planning Australia delivers initiatives to increase awareness and uptake of ACP among Australians. This study aimed to evaluate the reach and satisfaction with two unique volunteer-led ACP initiatives: a national advisory service and a community education program.

**Methods:** Volunteers were trained and mentored. Standard operating procedures and presentations guided service delivery, resulting in clearly documented program resources that can be used by other groups. Services were provided to consumers and health professionals. Follow-up measures included satisfaction with the advisory service and awareness, knowledge and confidence regarding ACP and the education program.

**Results:** During 1 January to 30 September 2018, the national advisory service received 1284 enquiries; 572 from health professionals, 712 from consumers. Fifty percent of calls were responded to by volunteers and 50% by health professionals. Sixty-two enquirers completed an evaluation survey, with 87% of those indicating that they were satisfied or extremely satisfied with the service.

During 30 May to 18 September 2018, volunteers delivered 15 presentations to 247 people. Of those, 149 attendees completed an evaluation survey. Prior to the session, 27% had never heard of ACP whereas 42% had. Post session, 76% of respondents indicated confidence to have ACP conversations with family and friends, 65% indicated confidence to talk to their healthcare professionals.

**Conclusion:** Volunteer-led models of service delivery can help meet organisational outcomes. Volunteers can deliver high rates of satisfaction and increase community confidence in having advance care planning conversations.

O02

### **SweACP: a structured conversation-based Advanced Care Planning approach in the ACP-naïve Swedish context**

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**Background:** Sweden has no systematic advance care planning (ACP), nor judicial means of recognizing proxies in end-of-life (EoL) situations. In the SweACP project in the DöBra research program, we focus on engaging stakeholders in active conversations about preferences for future EoL care, rather than using a document-driven approach to ACP. We describe results of feasibility testing a structured conversation-based ACP approach among older adults in the general public as well as exploring their strategies for reasoning about their EoL preferences.

**Methods:** After initial testing in pilot focus groups, a Swedish version of GoWish cards, DöBra cards, and Eco-mapping were used to catalyze discussions on what and who matters at the EoL. The 65 participants from across Sweden actively contacted the researchers volunteering to participate, after receiving information through national patient- or retiree organizations. Both quantitative and qualitative data were analyzed, using descriptive statistics and inductive analysis.

**Results:** DöBra cards were positively received by participants; there was great individual variation in card prioritization and formulation of wild cards. Eco-mapping was met with less enthusiasm but was useful in depicting a social context often taken-for-granted. Qualitative analysis revealed several strategies for reasoning about future EoL care.

**Conclusions:** Having a hands-on tool rather than just talking, and wild cards to open up conversations on possibly taboo subjects were noted strengths of DöBra cards, which also influenced participants' reasoning by shifting focus from hypothetical scenarios to more specific situations. We found the cards to be a feasible tool for stimulating person-centered conversations on EoL preferences.

O03

### **Knowledge, attitude, and experience of advance care planning among healthcare professionals in Asia: a systematic review**

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**Background:** Despite universal recognition of advance care planning's (ACP) importance, collectivism spirit in Asia may impact its uptake.

**Aims**

To gain insight into health care professionals' (HCP) knowledge of, attitude towards, and experience with ACP in Asia.

**Methods:** We systematically searched four electronic databases for quantitative and qualitative studies on ACP in East and South East Asian countries. Anticipating unfamiliarity with ACP, we operationalized ACP broadly, covering discussions about future medical care and documentation thereof.

**Results:** Among 3,358 identified studies, 41 were eligible; 36 applied quantitative and 5 applied qualitative design. Most studies were conducted in high-income countries: Japan (16), South Korea (13), Singapore (4), Hong Kong (4), and Taiwan (3). While twenty-nine studies addressed documentation of preferences, only six addressed ACP and end-of-life discussion respectively. Ten studies addressing knowledge indicated moderate awareness of ACP. Thirty

studies on attitudes showed that although many HCPs considered ACP and involving patient and family in its process important, some found initiating ACP difficult. This hesitation was partly due to fear of conflicts with family members and the legal consequences. Twenty studies on experiences indicated that actual engagement of HCP in ACP is limited, too late, and mostly only involved family without patients.

**Conclusion:** Although being considered potentially important, ACP did not occur often. HCPs seem to be reluctant to engage in ACP. The role of family in ACP is crucial in Asia. However, evidence was highly heterogeneous and limited to a few high-income countries, which limits its generalizability to other Asian countries.

#### O04

##### **The concept of ACP: perspectives of palliative care patients living in an urban area in Malaysia.**

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**Background:** What are the perspectives of palliative care patients living in an urban area in Malaysia on advance care planning? Exploratory study to shape the concept of advance care planning according to local understanding and needs.

**Methods:** This is a qualitative study, using semi-structured interviews with a purposive sampling of fifteen participants. All interviews were conducted in participants' homes. Interviews were audio-taped, transcribed verbatim and analysed. Thematic analysis was done through coding, theoretical sampling and finally integrating it into a conceptual framework.

**Results:** All participants did not know what advance care planning was but was receptive to the idea of planning ahead. The main theme emerged from this exploratory qualitative study was individualised non-medical planning. This was shaped by factors such as participant's spirituality, prior health-related experiences, perceived psychosocial burden and information received on diagnosis, prognosis and availability of resources.

**Conclusions:** The concept of advance care planning is foreign to palliative care patients living in Malaysia. Advance care planning is not seen as just purely medical-decision planning but it is seen as an interplay between psychosocial and relational factors. Palliative care patients in Malaysia vary considerably with regards to the extent to which they wish to engage in advance care planning discussion, but at the same time, may face barriers from healthcare professionals with poor communication skills. Awareness and education on advance care planning for both healthcare professionals and palliative care patients will eventually lead to improvement in end-of-life care planning.

#### O05

##### **A conversation card game motivates British Columbians to engage in advance care planning**

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**Background:** Advance care planning (ACP) is an important process that involves reflecting on, discussing and documenting one's values and preferences for future healthcare. A 2016 study in British Columbia (B.C.) showed that public engagement in ACP is low. The BC Centre for Palliative Care (BC-CPC) is leading a provincial initiative, in collaboration with various stakeholders, to promote early public engagement in ACP behaviours through innovative strategies. In 2016, BC-CPC partnered with 15 community-based organizations to assess the acceptability and effectiveness of a conversation card game in engaging the public in ACP conversations. Game questions are designed to stimulate conversations about issues relevant to decision making in the context of a serious illness.

**Methods:** Participants were recruited by convenience sampling using community advertisements. During the game, participants take turns drawing cards, reading the questions on the cards aloud, and writing down their answers before sharing them with the group. Quantitative data was collected using a structured questionnaire to assess the participants' experience and motivation to engage in ACP.

**Results:** Over 12 months, 547 British Columbian adults participated in 44 game events hosted by community organizations from across B.C. After playing the game, the majority of participants (90%) planned to continue the conversation with family, and 75% agreed that the game made the conversations about the discussed topics safe and meaningful.

**Conclusion:** Our findings indicate that playing the conversation game in a community setting is a feasible and effective way to motivate British Columbian to engage in ACP.

#### O06

##### **Primary care clinicians' confidence, willingness and participation in advance care planning discussions: a multi-site survey**

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**Background:** People who engage in advance care planning (ACP) are more likely to receive healthcare that is concordant with their goals and wishes at the end of life. Primary care providers are ideally positioned to facilitate ACP. This study sought to describe the confidence, willingness and participation of primary care clinicians to have advance care planning discussions.

**Methods:** We conducted a survey of family physicians and allied health professionals (AHP) in primary care in three Canadian provinces. We asked about willingness and confidence to have ACP discussions and current participation on Likert-type scales (0=not at all, 6=an extreme amount). A modified Dillman approach was used for online survey administration.

**Results:** The response rate was 72% (n=117) among physicians and 69% (n=62) among allied health professionals.

Most physicians (77%) were practicing in an interprofessional practice. The mean willingness to initiate ACP was 5.0 for physicians and 4.8 for AHP. Mean confidence ratings for initiating ACP was 4.8 for physicians and 3.5 for AHP. Current participation in ACP among patients aged 50 years and older was lower; 2.6 for physicians and 1.4 for AHP. **Conclusions:** The willingness of family physicians and AHP in primary care to initiate ACP discussions with patients is high. However, confidence is only moderate in AHP and actual activity is low for all clinicians. Efforts to remove barriers in primary care and provide support for AHP to improve their confidence to engage in ACP discussions should be priorities.