SFAP

1ER COLLOQUE INTERNATIONAL ADVANCE CARE PLANNING (ACP)

ACP dans le monde - ACP en France.
Du concept international à la mise en œuvre française

1ST INTERNATIONAL ADVANCE CARE PLANNING (ACP) SYMPOSIUM

ACP in the world - ACP in France.
From an international context to implementation in France

What is Advance Care Planning?

Craig Sinclair Ph.D
University of New South Wales, School of Psychology

Paris, vendredi 7 février 2025

Disclosure of Interests

Liens d'intérêts déclarés par l'intervenant :

Older Persons Advocacy Network (Australia)

Advance Care Planning Australia

Advance Care Planning International

mention de la nature du ou des liens d'intérêts (à décrire)

Consultancy and Advice, some of this work is subject to financial reimbursement (e.g. travel expenses) or payment for services rendered

- Brief modern history
- What is advance care planning?
- Implications for policy and practice


@steven_w

A Brief Modern History

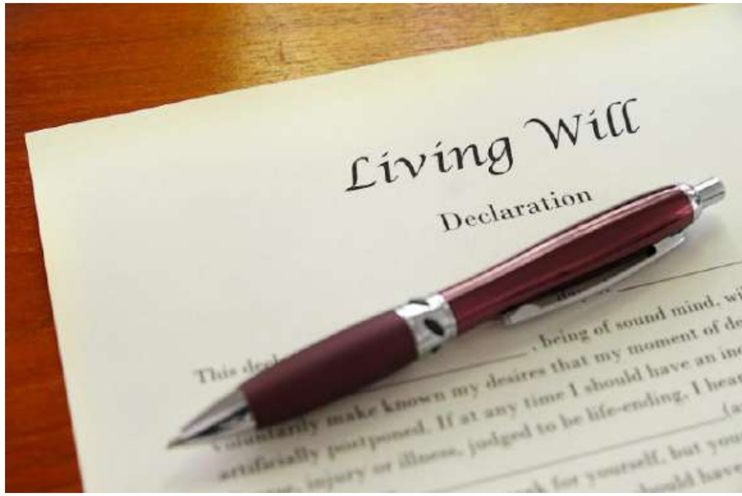
Quinlan case

1970's

First living will statutes

Durable powers of attorney

1980's



Living Will

Declaration

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SUPPORT Trial

1995-2000

Schiavo case

1998-2005

SPECIAL ARTICLES

Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention

Joan Teno, MD, MS,[*] Joanne Lynn, MD,[*] Neil Wenger, MD,[†] Russell S. Phillips, MD,[‡] Donald P. Murphy, MD,[§] Alfred F. Connors, Jr., MD,[¶] Norman Desbiens, MD,[**] William Fulkerson, MD,[††] Paul Bellamy, MD,[†] and William A. Knaus, MD[‡‡] for the SUPPORT Investigators

OBJECTIVE: To assess the effectiveness of written advance directives (ADs) in the care of seriously ill, hospitalized patients. In particular, to conduct an assessment after ADs were promoted by the Patient Self-Determination Act (PSDA) and enhanced by the effort to improve decision-making in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), focusing upon the impact of ADs on decision-making about resuscitation.

DESIGN: Observational cohort study conducted for 2 years before (PRE) and for 2 years after (POST) the PSDA, with a randomized, controlled trial of an additional intervention to improve decision-making after the PSDA (POST+SUPPORT).

SETTING: Five teaching hospitals in the United States

PATIENTS: A total of 9105 seriously ill patients treated in five teaching hospitals.

INTERVENTIONS: The PSDA mandated patient education about ADs at hospital entry and documentation of ADs in the medical record. The SUPPORT intervention, in addition, provided a nurse to facilitate communication among patients, surrogates, and physicians about preferences for and outcomes of treatment alternatives and, when clinically appropriate, to encourage completion and utilization of ADs.

MEASUREMENTS: Interviews were conducted with patients, surrogates, and attending physicians about awareness, completion, and impact of ADs. Medical records were reviewed for discussion about preferences concerning resuscitation, timing and writing of "Do Not Resuscitate" (DNR) orders, evidence of ADs, and the use or forgoing of resuscitation at the time of death.

RESULTS: In the three cohorts, PRE, POST, and POST+SUPPORT, average age was 63. One-quarter of patients died during the initial hospitalization, one-half were dead within 6 months, and one-half were unconscious for their last 3 days. Before the PSDA (PRE), 62% were familiar with a living will, and 21% had an AD. These rates were similar for the POST and POST+SUPPORT cohorts. Just 36 (6%) of these directives were mentioned in the medical records for PRE, but a stable 35% were documented for POST, and POST+SUPPORT had an increasing rate averaging 78% ($P < .001$).

As previously reported for PRE patients, the POST patients with and without ADs had no significant differences in the rates of medical record documentation of discussions about resuscitation (33% vs 38%, POST without AD vs POST with AD), DNR orders among those who wanted to forgo resuscitation (54% vs 58%), and attempted resuscitations at death (17% vs 9%). The POST+SUPPORT patients had similar results, with no evidence that the intervention enhanced the effect of ADs on these three measures of resuscitation decision-making. Patients with ADs more often reported that preferences about resuscitation were discussed with a physician (e.g., for POST patients, 30% for those with no AD and 43% for those with an AD, $P < .05$).

Only 12% of patients with ADs had talked with a physician when completing the AD. Only 42% reported ever having discussed the AD with their physician. By the second study week, only one in four physicians was aware of patients' ADs.

CONCLUSIONS: In these seriously ill patients, ADs did not substantially enhance physician-patient communication or decision-making about resuscitation. This lack of effect was not altered by the PSDA or by the enhanced efforts in SUPPORT, although these interventions each substantially increased documentation of existing ADs. Current practice patterns indicate that increasing the frequency of ADs is unlikely to be a substantial element in improving the care of seriously ill patients. Future work to improve decision-making should focus upon improving the current pattern of practice through better communication and more comprehensive advance care planning. **J Am Geriatr Soc 45:500–507, 1997.**

For editorial comment, see p 519

From the [*]Center to Improve Care of the Dying, The George Washington University, Washington, DC; [†]University of California at Los Angeles Medical Center, Los Angeles, CA; [‡]Beth Israel Hospital, Boston, MA; [§]St. Luke's Presbyterian Hospital, Denver CO; [¶]MetroHealth Medical Center, Cleveland, OH; [**]Marshfield Clinic and Marshfield Medical Research Foundation, Marshfield, WI; [††]Duke University Hospital, Durham, NC; and [‡‡]The Department of Health Evaluation Sciences, The University of Virginia School of Medicine, Charlottesville, VA.

This research was made possible by funding from the Robert Wood Johnson Foundation's Program on the Care of Critically Ill Hospitalized Adults: SUPPORT The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, and from Grant number 1 RO1 HS07075 from the Agency for Health Care Policy and Research. The opinions and findings in this manuscript are those of the authors and do not necessarily represent the views of the sponsors.

Address correspondence and reprint requests to Joan M. Teno, MD, MS, Center to Improve Care of the Dying, George Washington University Medical Center, 1001 22nd St., NW, Ste. 820, Washington, DC 20037.

JAGS 45:500–507, 1997
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0002-8614/97/$3.50

Reach and Impact of a Mass Media Event Among Vulnerable Patients: The Terri Schiavo Story

Rebecca L. Sudore, MD[1,2,3], C. Seth Landefeld, MD[1,2,3], Steven Z. Pantilat, MD[3], Kathryn M. Noyes, BS[1,2], and Dean Schillinger, MD[3,4]

INTRODUCTION

METHODS

1854

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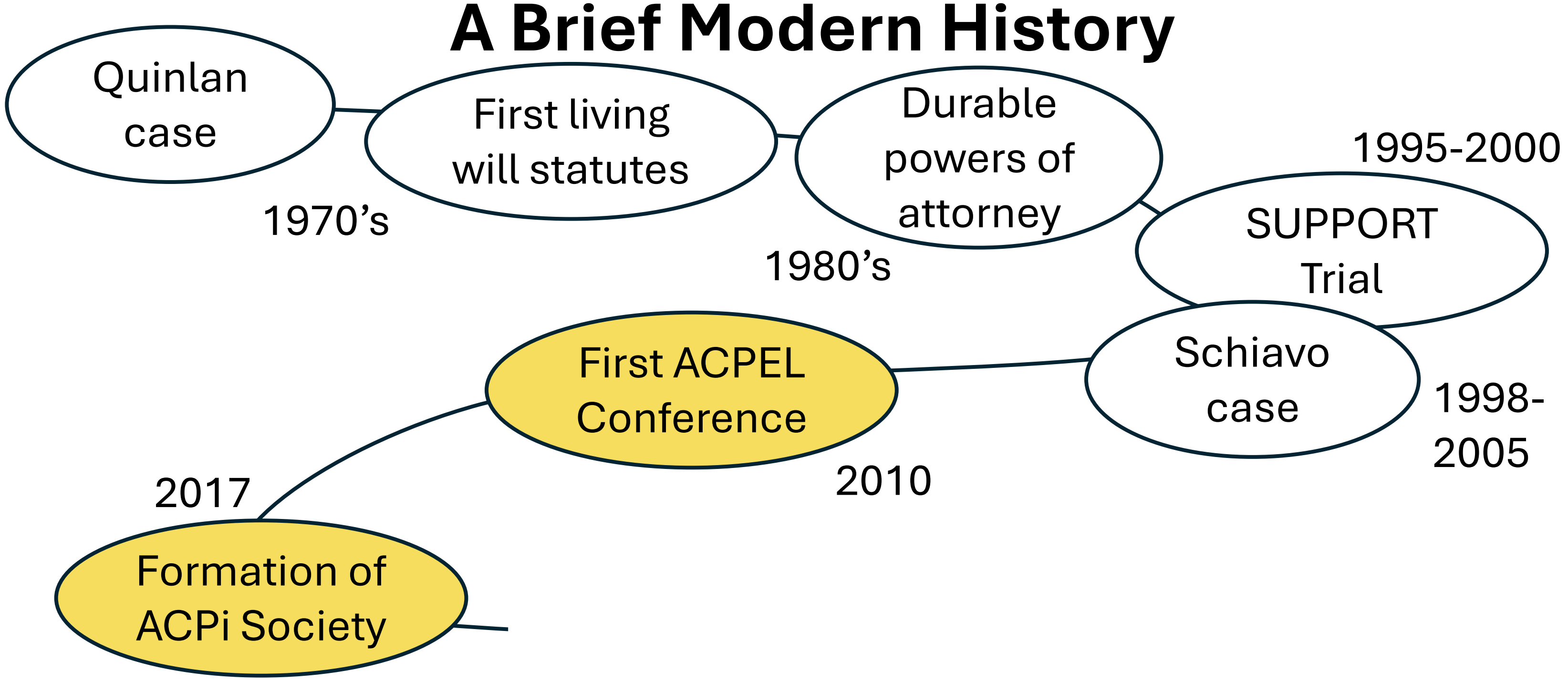
(Teno et al. 1997, *JAGS 45*:500-507)

A Brief Modern History



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First ACPEL Conference

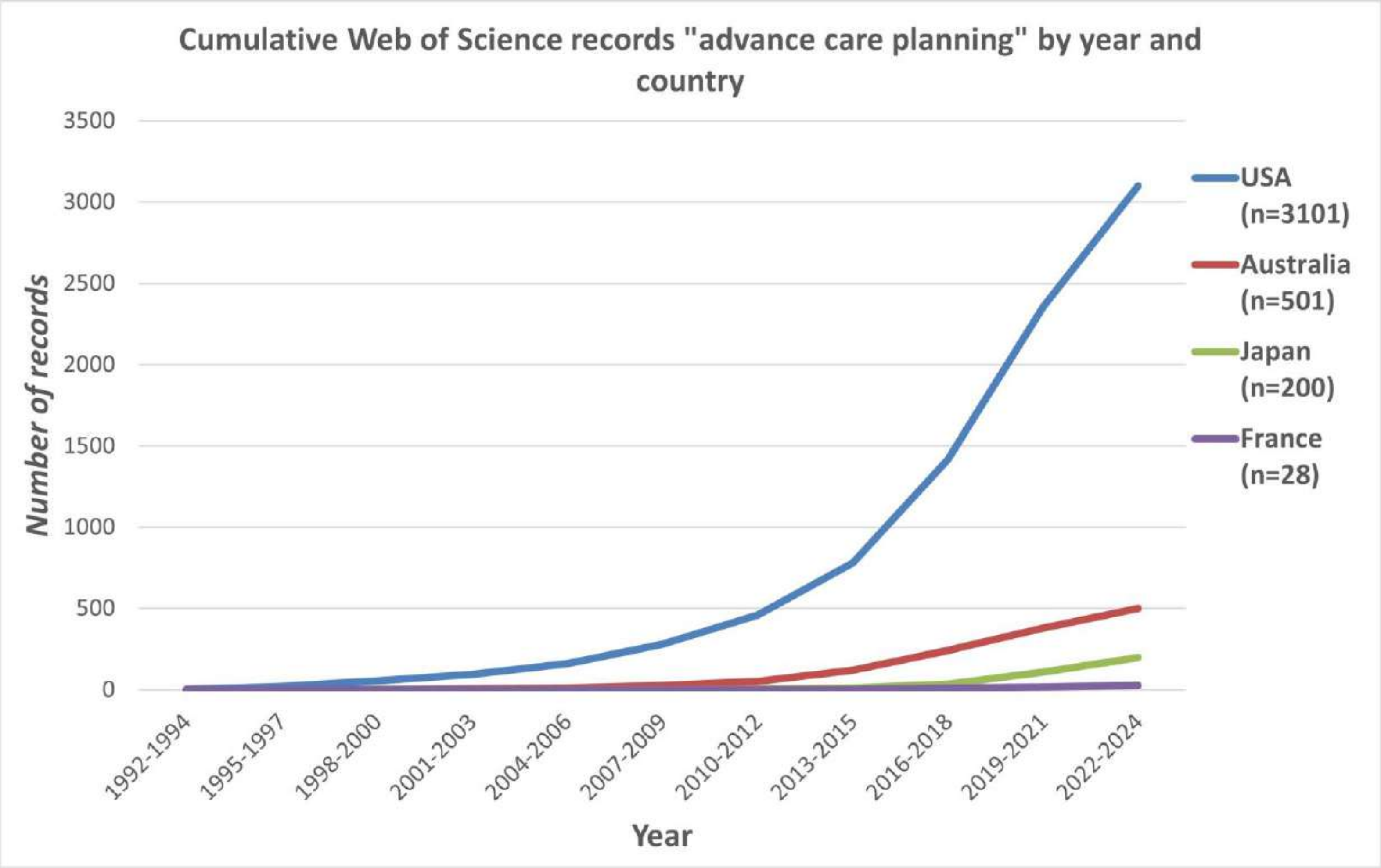
2010

2017

Formation of ACPi Society

https://www.acp-i.org/

Advance Care Planning in the International Literature



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A Brief Modern

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Original Article

PALLIATIVE MEDICINE

Definition and recommendations of advance care planning: A Delphi study in five Asian sectors

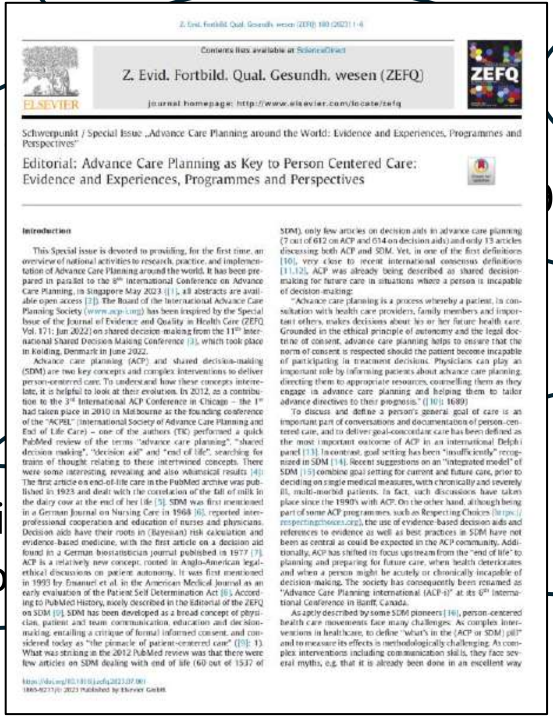
Masanori Mori[1], Helen Y. L. Chan[2], Cheng-Pei Lin[3,4], Sun-Hyun Kim[5], Raymond Ng Han Lip[6], Diah Martina[7,8,9,10], Kwok Keung Yuen[11], Shao-Yi Cheng[12], Sayaka Takenouchi[13], Sang-Yeon Suh[14,15], Sumytra Menon[16], Jungyoung Kim[17], Ping-Jen Chen[18,19], Futoshi Iwata[20], Shimon Tashiro[21], Oi Ling Annie Kwok[22], Jen-Kuei Peng[12], Hsien-Liang Huang[12], Tatsuya Morita[1], Ida J. Korfage[8], Judith A. C. Rietjens[8,23] and Yoshiyuki Kizawa[24]

Abstract

Background: In Confucian-influenced Asian societies, explicit end-of-life conversations are uncommon and family involvement in decision making is crucial, which complicates the adoption of culturally sensitive advance care planning.

Aim: To develop a consensus definition of advance care planning and provide recommendations for patient-centered and family-based initiatives in Asia.

Design: A five-round Delphi study was performed. The rating of a definition and 84 recommendations developed based on systematic reviews was performed by experts with clinical or research expertise using a 7-point Likert scale. A median = 1 and an inter-quartile range = 0–1 were considered very strong agreement and very strong consensus, respectively.



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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives“

Editorial: Advance Care Planning as Key to Person Centered Care: Evidence and Experiences, Programmes and Perspectives

Review

Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

Judith A C Rietjens, Rebecca L Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Droger, Agnes van der Heide, Daren K Heyland, Dirk Houttekier, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Jox, Ida J Korfage, on behalf of the European Association for Palliative Care

Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. We used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application. Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68–100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. We present a list of outcome measures to enable the pooling and comparison of results of ACP studies. We believe that our recommendations can provide guidance for clinical practice, ACP policy, and research.

Vol. 53 No. 5 May 2017 Journal of Pain and Symptom Management 821

Original Article

Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

Rebecca L. Sudore, MD, Hillary D. Lum, MD, PhD, John J. You, MD, Laura C. Hanson, MD, MPH, Diane E. Meier, MD, Steven Z. Pantilat, MD, Daniel D. Matlock, MD, MPH, Judith A.C. Rietjens, PhD, Ida J. Korfage, MSc, PhD, Christine S. Ritchie, MD, MSPH, Jean S. Kutner, MD, MSPH, Joan M. Teno, MD, MS, Judy Thomas, JD, Ryan D. McMahan, BS, BA, and Daren K. Heyland, MD, MSc

Abstract

Context. Despite increasing interest in advance care planning (ACP) and previous ACP descriptions, a consensus definition does not yet exist to guide clinical, research, and policy initiatives.

Objective. The aim of this study was to develop a consensus definition of ACP for adults.

Methods. We convened a Delphi panel of multidisciplinary, international ACP experts consisting of 52 clinicians, researchers, and policy leaders from four countries and a patient/surrogate advisory committee. We conducted 10 rounds using a modified Delphi method and qualitatively analyzed panelists' input. Panelists identified several themes lacking consensus and iteratively discussed and developed a final consensus definition.

Results. Panelists identified several tensions concerning ACP concepts such as whether the definition should focus on conversations vs. written advance directives; patients' values vs. treatment preferences; current shared decision making vs. future medical decisions; and who should be included in the process. The panel achieved a final consensus one-sentence definition and accompanying goals statement: "Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." The panel also described strategies to best support adults in ACP.

Conclusions. A multidisciplinary Delphi panel developed a consensus definition for ACP for adults that can be used to inform implementation and measurement of ACP clinical, research, and policy initiatives. J Pain Symptom Manage 2017;53:821–832. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words
Advance care planning, consensus, Delphi technique, policy making

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2017

ACP Delphi consensus studies

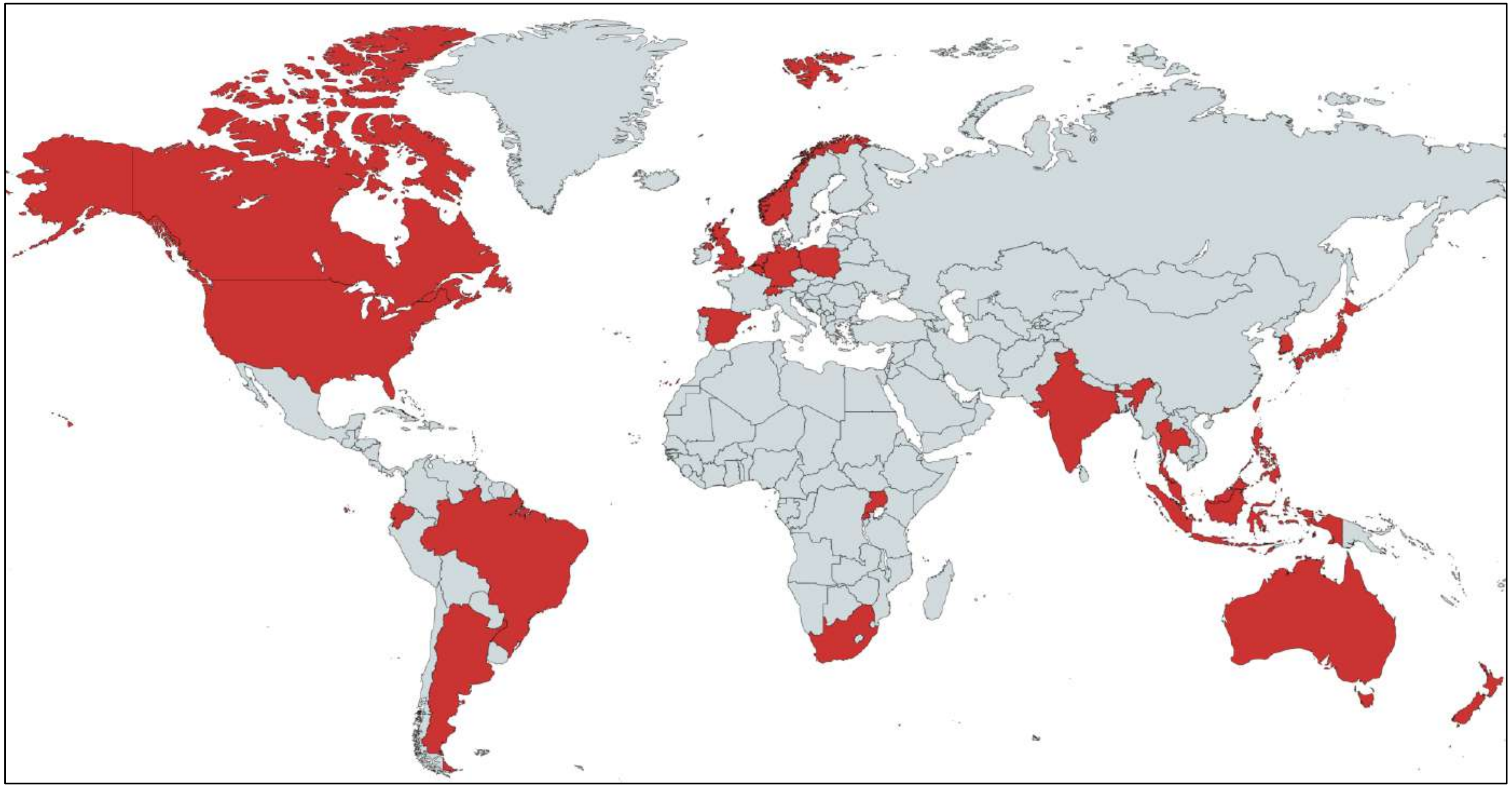
2022

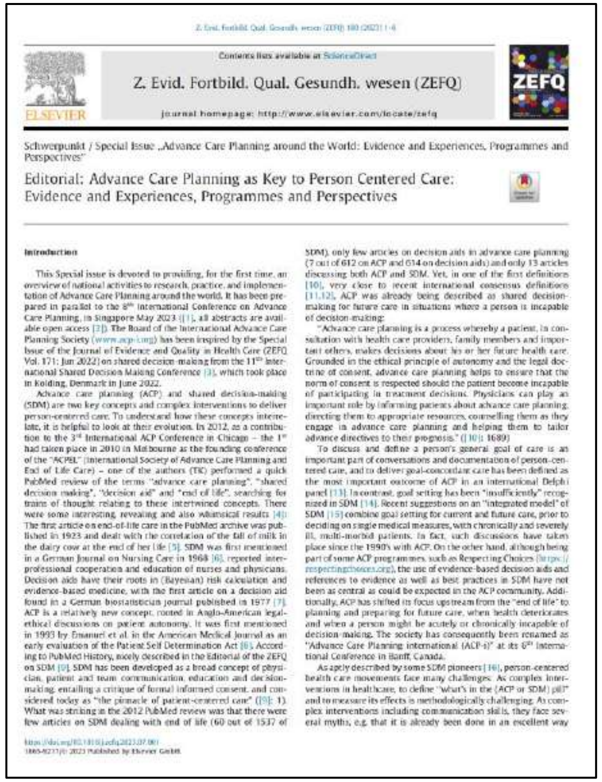
ZEFQ Special Issue

Asia Pacific Delphi consensus study

Paris, 07 février 2025

Advance Care Planning – Becoming More International





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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives"

Editorial: Advance Care Planning as Key to Person Centered Care: Evidence and Experiences, Programmes and Perspectives

Introduction

This Special issue is devoted to providing, for the first time, an overview of national activities to research, practice, and implementation of Advance Care Planning around the world. It has been prepared in parallel to the 8th International Conference on Advance Care Planning, in Singapore May 2023 ([1], all abstracts are available open access [2]). The Board of the International Advance Care Planning Society (www.acp-i.org) has been inspired by the Special Issue of the Journal of Evidence and Quality in Health Care (ZEFQ Vol. 171: Jun 2022) on shared decision-making from the 11th International Shared Decision Making Conference [3], which took place in Kolding, Denmark in June 2022.

Advance care planning (ACP) and shared decision-making (SDM) are two key concepts and complex interventions to deliver person-centered care. To understand how these concepts interrelate, it is helpful to look at their evolution. In 2012, as a contribution to the 3rd International ACP Conference in Chicago – the 1st had taken place in 2010 in Melbourne as the founding conference of the "ACPEL" (International Society of Advance Care Planning and End of Life Care) – one of the authors (TK) performed a quick PubMed review of the terms "advance care planning", "shared decision making", "decision aid" and "end of life", searching for trains of thought relating to these intertwined concepts. There were some interesting, revealing and also whimsical results [4]: The first article on end-of-life care in the PubMed archive was published in 1923 and dealt with the correlation of the fall of milk in the dairy cow at the end of her life [5]. SDM was first mentioned in a German Journal on Nursing Care in 1968 [6], reported interprofessional cooperation and education of nurses and physicians. Decision aids have their roots in (Bayesian) risk calculation and evidence-based medicine, with the first article on a decision aid found in a German biostatistician journal published in 1977 [7]. ACP is a relatively new concept, rooted in Anglo-American legal-ethical discussions on patient autonomy. It was first mentioned in 1993 by Emanuel et al. in the American Medical Journal as an early evaluation of the Patient Self Determination Act [8]. According to PubMed History, nicely described in the Editorial of the ZEFQ on SDM [9], SDM has been developed as a broad concept of physician, patient and team communication, education and decision-making, entailing a critique of formal informed consent, and considered today as "the pinnacle of patient-centered care" ([9]: 1). What was striking in the 2012 PubMed review was that there were few articles on SDM dealing with end of life (60 out of 1537 of SDM), only few articles on decision aids in advance care planning (7 out of 612 on ACP and 614 on decision aids) and only 13 articles discussing both ACP and SDM. Yet, in one of the first definitions [10], very close to recent international consensus definitions [11,12], ACP was already being described as shared decision-making for future care in situations where a person is incapable of decision-making:

"Advance care planning is a process whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care. Grounded in the ethical principle of autonomy and the legal doctrine of consent, advance care planning helps to ensure that the norm of consent is respected should the patient become incapable of participating in treatment decisions. Physicians can play an important role by informing patients about advance care planning, directing them to appropriate resources, counselling them as they engage in advance care planning and helping them to tailor advance directives to their prognosis." ([10]: 1689)

To discuss and define a person's general goal of care is an important part of conversations and documentation of person-centered care, and to deliver goal-concordant care has been defined as the most important outcome of ACP in an international Delphi panel [13]. In contrast, goal setting has been "insufficiently" recognized in SDM [14]. Recent suggestions on an "integrated model" of SDM [15] combine goal setting for current and future care, prior to deciding on single medical measures, with chronically and severely ill, multi-morbid patients. In fact, such discussions have taken place since the 1990's with ACP. On the other hand, although being part of some ACP programmes such as Respecting Choices (https://respectingchoices.org/), the use of evidence-based decision aids and references to evidence as well as best practices in SDM have not been as central as could be expected in the ACP community. Additionally, ACP has shifted its focus upstream from the "end of life" to planning and preparing for future care, when health deteriorates and when a person might be acutely or chronically incapable of decision-making. The society has consequently been renamed as "Advance Care Planning international (ACP-i)" at its 6th International Conference in Banff, Canada.

As aptly described by some SDM pioneers [16], person-centered health care movements face many challenges: As complex interventions in healthcare, to define "what's in the (ACP or SDM) pill" and to measure its effects is methodologically challenging. As complex interventions including communication skills, they face several myths, e.g. that it is already been done in an excellent way

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A Brief Modern

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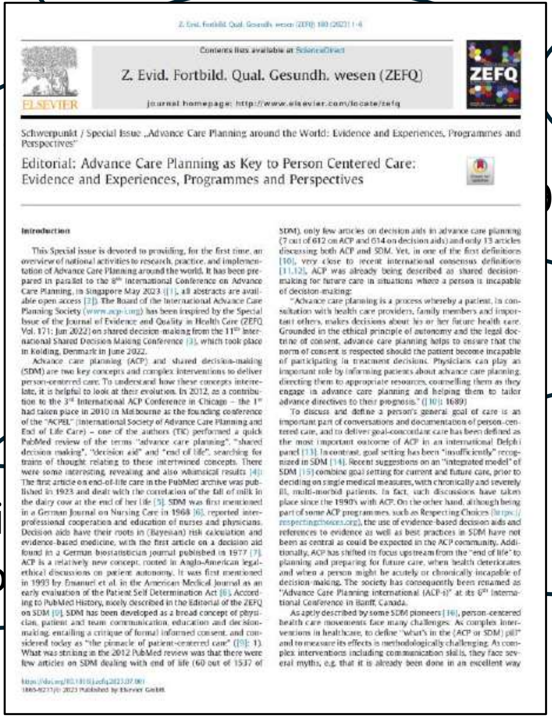

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Introduction

Advance care planning (ACP) enables individuals to make plans about their future health care. Robust evidence from systematic reviews shows that ACP increases the completion of advance care directives and occurrence of discussions about future health care in

ACP too early could lead to a reluctance to engage in ACP, whilst engaging in ACP in the face of a crisis or shortly before dying could be too late. A third challenge in ACP is that differences in patient preference, knowledge, and health literacy could complicate navigation of ACP by health-care professionals. Finally,

Original Article

Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

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Paris, 07 février 2025

‘Respecting Patient Choices’ trial

Participants:
- N = 309 medically unwell, hospital inpatients, >80 years of age, with decision-making capacity

Intervention:
- A nurse or social worker led facilitated ACP discussion/s
- Randomly allocated to ‘usual care’ or ‘usual care + facilitated ACP’
- Followed up for 6 months or until death

Outcomes:
- 125/154 accepted ACP discussion. 84% wrote down preferences and/or appointed a substitute decision-maker
- Of 56 who died during the follow-up period: end of life wishes more likely to be known and followed (86% vs 30%, *p* <.001)
- Significantly less symptoms of anxiety, depression and post-traumatic stress among bereaved family members

BMJ

RESEARCH

The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,[1] Andrew D Hancock, project officer,[1] Michael C Reade, physician,[2] William Silvester, intensive care physician and director[1]

ABSTRACT

Detering, K., et al. (2010). The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. *British Medical Journal, 340. doi:10.1136/bmj.c1345*

What is Advance Care Planning?

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Original Article

Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

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Abstract

Context. Despite increasing interest in advance care planning (ACP) and previous ACP descriptions, a consensus definition does not yet exist to guide clinical, research, and policy initiatives.

Objective. The aim of this study was to develop a consensus definition of ACP for adults.

Methods. We convened a Delphi panel of multidisciplinary, international ACP experts consisting of 52 clinicians, researchers, and policy leaders from four countries and a patient/surrogate advisory committee. We conducted 10 rounds using a modified Delphi method and qualitatively analyzed panelists' input. Panelists identified several themes lacking consensus and iteratively discussed and developed a final consensus definition.

Results. Panelists identified several tensions concerning ACP concepts such as whether the definition should focus on conversations vs. written advance directives; patients' values vs. treatment preferences; current shared decision making vs. future medical decisions; and who should be included in the process. The panel achieved a final consensus one-sentence definition and accompanying goals statement: "Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." The panel also described strategies to best support adults in ACP.

Conclusions. A multidisciplinary Delphi panel developed a consensus definition for ACP for adults that can be used to inform implementation and measurement of ACP clinical, research, and policy initiatives. J Pain Symptom Manage 2017;53:821–832. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words
Advance care planning, consensus, Delphi technique, policy making

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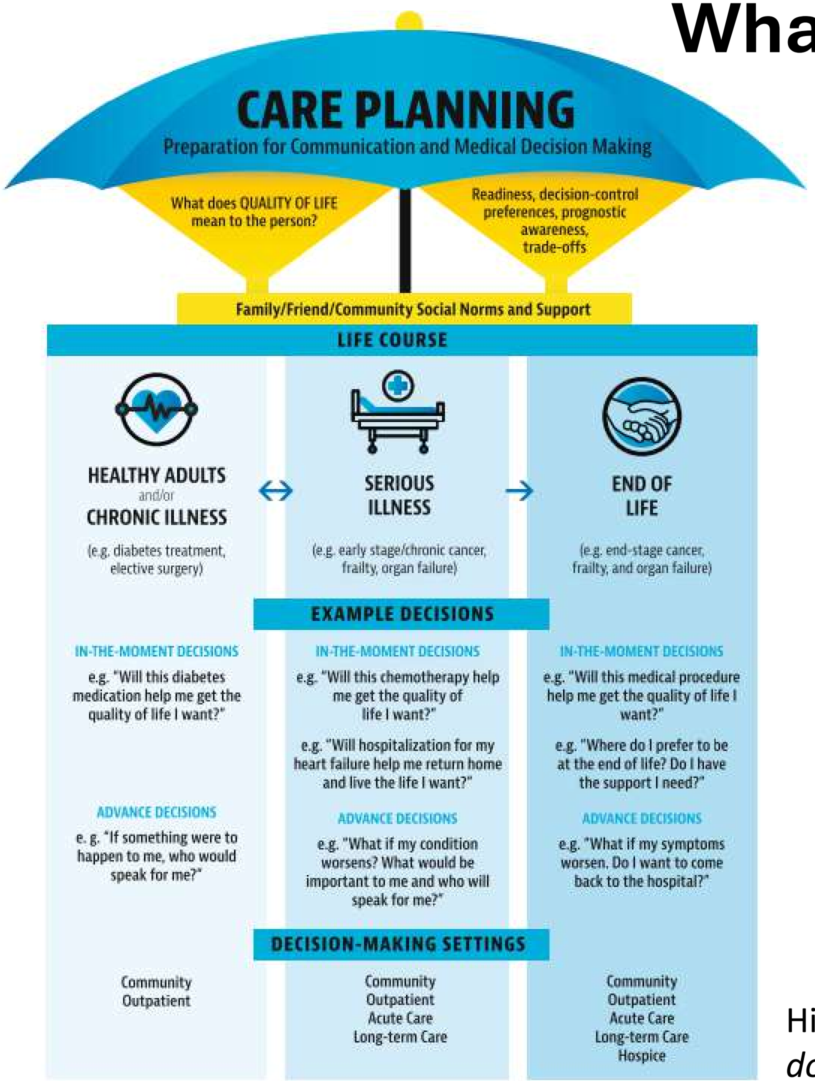
What is Advance Care Planning?



CARE PLANNING
Preparation for Communication and Medical Decision Making

What does QUALITY OF LIFE mean to the person?

Readiness, decision-control preferences, prognostic awareness, trade-offs

Family/Friend/Community Social Norms and Support

LIFE COURSE

HEALTHY ADULTS and/or CHRONIC ILLNESS ↔	SERIOUS ILLNESS →	END OF LIFE
(e.g. diabetes treatment, elective surgery)	(e.g. early stage/chronic cancer, frailty, organ failure)	(e.g. end-stage cancer, frailty, and organ failure)
EXAMPLE DECISIONS		
IN-THE-MOMENT DECISIONS e.g. "Will this diabetes medication help me get the quality of life I want?"	IN-THE-MOMENT DECISIONS e.g. "Will this chemotherapy help me get the quality of life I want?" e.g. "Will hospitalization for my heart failure help me return home and live the life I want?"	IN-THE-MOMENT DECISIONS e.g. "Will this medical procedure help me get the quality of life I want?" e.g. "Where do I prefer to be at the end of life? Do I have the support I need?"
ADVANCE DECISIONS e. g. "If something were to happen to me, who would speak for me?"	ADVANCE DECISIONS e.g. "What if my condition worsens? What would be important to me and who will speak for me?"	ADVANCE DECISIONS e.g. "What if my symptoms worsen. Do I want to come back to the hospital?"
DECISION-MAKING SETTINGS		
Community Outpatient	Community Outpatient Acute Care Long-term Care	Community Outpatient Acute Care Long-term Care Hospice

"As the field has evolved, this definition focused on "future decisions" has proven to be too narrow..."

"...we must reconceptualize advance care planning as a holistic process over the life course, that includes both in-the-moment and advanced decisions at every life stage."

- Preparation for communication and decision-making across different settings and different stages of the illness trajectory
- Identifying and supporting appropriate 'in-the-moment' and anticipatory decisions at each stage

Hickman, S. et al. *Journal of the American Geriatrics Society, 71(7), 2350-2356. doi:https://doi.org/10.1111/jgs.18287*

What is Advance Care Planning? – Components of Advance Care Planning

Finding a starting point

- Not just ‘decision-making capacity’
- Understanding patient readiness to engage in advance care planning
- Patient and carer understanding of existing condition
- Cultural background and family context
- How will communication occur? With whom?

“I often ask my patients questions to understand what is important to them in their care. Is this ok for you?”

“What do I need to know about you to be able to provide the best possible care?”

“Can you tell me, in your own words, what you understand of your current health condition/s?”

What is Advance Care Planning? – Components of Advance Care Planning

Elaborating values and goals

- Collaboratively identified goals, grounded in values and past experiences
- Values clarification activities
- Identifying preferred substitute decision-maker/s

Education about advance care planning options

- The sorts of discussions that could be helpful, and who might be involved
- Introducing formal tools for documenting advance care planning
- Education on practical requirements

"What I'm hearing you saying is that XXXXXXX is really important to you. Is that right?"

"It's great that you are talking about this with XXXXXX. Would it be ok if we talked about this all together?"

"We can also help you to document this, to make your wishes clearer for XXXXXX…"

What is Advance Care Planning? – Components of Advance Care Planning

Articulating preferences

- Explore scenarios and treatment options relevant to condition and likely prognosis
- Emphasise ‘goals of care’, consider ‘limits or trials of treatment’
- Avoid jargon, use functional language

Assistance with documentation

- Facilitating discussions with preferred substitute decision-maker/s
- Assistance in translating functional, values-based language into actionable directions for clinicians
- Meeting legal requirements (e.g. witnessing)

“Based on what I hear you saying, it sounds to me like if XXXXXXX happened, and you were no longer able to communicate with the people around you, you would find it very difficult, maybe unbearable?”

“…if you were unable to walk…”
“…if you were unable to swallow…”

What is Advance Care Planning? – Components of Advance Care Planning

Sharing information

- Routine screening questions
- Receiving, vetting, storing and sharing documented preferences
- Consistent location for ACP documents
- Clinical alerts
- Identifying triggers for review

Providing responsive care

- ACDs into actionable medical orders
- Don't assume lack of decision capacity
- Enacting preferences
- Orchestrating care across settings
- Continuing support for substitute decision-makers

"Advance care planning documents are stored in the electronic medical record system and the front page of the patient's file."

"It is important for XXXXXXX that they can be at home for end-of-life care. How can we make this happen?"

Advance Care Planning Delivery Models : A Simple Typology

Key Health Professional

- General Practitioner, Medical Specialist, Care Home Manager etc.
- Existing clinical relationship
- ACP skills grounded in clinical experience rather than specialist training

Specialist ACP Facilitator

- e.g. Nurse, Social Worker, Allied Health
- Usually no prior clinical relationship
- Specialist ACP skills and experience
- May benefit from clinical collaboration with specialist or usual care team

Opportunistic delivery in routine care

- Social Worker, Community Nurse, Emergency Department Physician, Palliative care team
- Usually no prior clinical relationship
- ACP knowledge grounded in clinical experience
- Responsive to acute need or patient readiness

Grassroots community engagement

- Community worker, researcher, death doula, patient advocate
- Variable ACP skills and clinical experience
- Can empower community to take ownership and seek knowledge
- Benefit from clinical input and partnerships

Structural Factors

https://vimeo.com/288663901

- Systems for making documented preferences available to clinicians at point of care
- Quality control of incoming documents
- Real-time updates
- Increased rates of goal-concordant care and reduced healthcare costs

Open access
Original research

BMJ Open

Association of advance care planning with hospital use and costs at the end of life: a population-based retrospective cohort study

Ian Scott,[1,2] Liz Reymond,[3,4] Xanthe Sansome,[5] Hannah Carter[6]

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ABSTRACT

Objective To investigate associations between the availability and timing of digitally available advance care planning (ACP) documents and hospital use and costs during the last 6 months of life.
Design Retrospective population-based cohort study using data linkage.
Setting 11 public hospitals in Queensland, Australia.
Participants 5586 decedents with ACP documents were directly matched 1:2 to 11 172 control decedents based on age category, sex, location, year of death and principal diagnosis code for the last-known hospital admission.
Exposure ACP discussions with documents uploaded to a widely accessible statewide digital platform. Directly matched subgroup analyses investigated differences between decedents with ACP documents available at three different times prior to death: ≥6 months, between 1 and 6 months, and <1 month.
Main outcomes and measures Emergency department (ED) presentations, hospital and intensive care unit (ICU) admissions, and in-hospital deaths, expressed as adjusted OR (aOR). Secondary outcomes were hospital bed-days and costs.
Results ACP decedents with documents uploaded ≥6 months prior to death, compared with controls, had fewer ED presentations (aOR 0.90, 95% CI 0.81 to 1.00), hospitalisations (aOR 0.83, 95% CI 0.74 to 0.92), ICU admissions (aOR 0.23, 95% CI 0.10 to 0.48), and in-hospital deaths (aOR 0.56, 95% CI 0.51 to 0.63), and lower adjusted mean hospital costs per person over the last 6 months of life ($A2290 less (95% CI −$4116 to −$463)). Conversely, decedents with ACP documents uploaded less than 6 months prior to death showed higher rates of ED presentations and hospital admissions and greater hospital costs relative to controls.
Conclusion The association between digitally available ACP documents and health service use and cost differed based on the timing of ACP upload, with documents available ≥6 months prior to death being associated with less hospital use and costs.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Large multisite longitudinal analysis of standardised, patient-linked data on consecutive episodes of hospital care for almost 17 000 decedents, providing generalisable estimates of advance care planning (ACP) effects on hospital utilisation, costs and place of death.
- ⇒ Use of a matched cohort design compensated for the logistical difficulties of performing large randomised controlled trials, and where assigning patients to a no-ACP arm may be deemed unethical.
- ⇒ Observational design precludes confirmation of causal relationships between ACP and measured outcomes.
- ⇒ Inability to access data to control for potentially important but unmeasured confounders such as clinical status and disease severity, frailty, comorbidity burden and levels of psychosocial support.
- ⇒ Analyses were hospital focussed such that utilisation and costs of non-hospital care were not ascertained.

INTRODUCTION

Advance care planning (ACP) is the iterative process of defining and documenting a person's values and preferences to guide future healthcare delivery.[1] Evidence shows ACP decreases anxiety, grief, decisional conflict and burden for surviving relatives and surrogates,[2-4] enhances clinician adherence to patient preferences, increases use of palliative care, improves patient and family satisfaction with care and avoids unwanted cardiopulmonary resuscitation (CPR) and life-support treatments.[5-7] Considerable expenditure on end-of-life care[8 9] may not improve care quality,[10] and aggressive treatment may violate patient preferences[11] or prove non-beneficial.[12 13]

Whether ACP reduces healthcare use and cost is unclear,[14 15] especially when ACP uptake occurs in less than 50% of eligible patients[16] and multiple implementation barriers exist,[17] including inaccessibility of ACP documentation when needed, and up to 75% of ACP documents being of poor quality.[18] The findings of economic evaluations of ACP vary according to their definitions of how and who provides ACP

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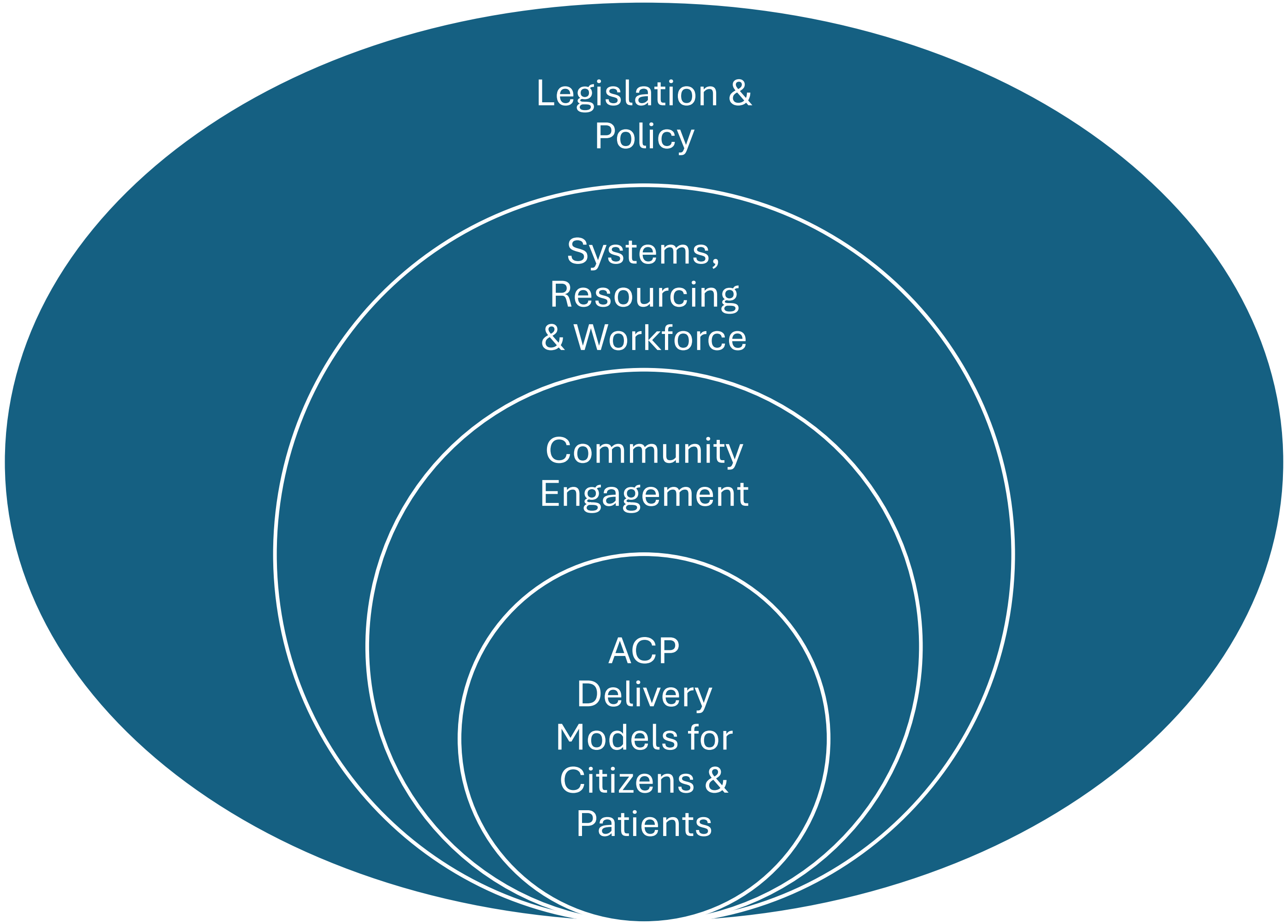
Scott, I., et al. (2024). *BMJ Open, 14(11), e082766. doi:10.1136/bmjopen-2023-082766*

A National Approach to Advance Care Planning?



Legislation & Policy

Systems, Resourcing & Workforce

Community Engagement

ACP Delivery Models for Citizens & Patients

"I am confident that I will receive care that is aligned with my values and goals and that my preferences will be known and respected"

"I work in an integrated and flexible healthcare system in which patient preferences are routinely elicited and communicated to relevant clinicians, enabling ***responsive*** care aligned with patient values, goals and preferences"

9th Advance Care Planning International Conference

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Advance Care Planning Australia is delighted to announce these keynote speakers. Keep an eye out for our next speaker announcement!

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Duke-NUS Medical School
National University of Singapore

Rebecca Sudore
University of California San Francisco

Liz Reymond
Co-Director Statewide Office of Advance Care Planning, Australia

Cindy Paardekooper
National Aboriginal and Torres Strait Islander Palliative Care Association Inc, Australia

Christian Ntzimira
African Center for Research on End-of-Life Care Research on End-of-Life Care

Abstract submissions now open

24 - 26 September
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https://www.acp-i2025.org/

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