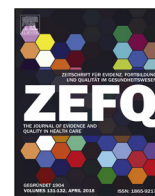




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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives“

## 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 8<sup>th</sup> 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](http://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 11<sup>th</sup> 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 3<sup>rd</sup> International ACP Conference in Chicago – the 1<sup>st</sup> 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 inter-professional 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 6<sup>th</sup> 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

by all health care practitioners or, on the contrary, that patients don't want ACP or SDM. Underlying many of these myths and discussions in the scientific, political, and societal sphere, is that person-centered care in fact – and on a much broader scale – challenges paternalism, that is still very powerful. Some of these tensions have been articulated in an ACP-i board letter [17], adding to a recent debate about the supposed effectiveness of ACP [18]. ACP is a complex evidence-based intervention, rooted in societal movements and ethical principles to honor wishes and values of persons, to base health care on what matters most to patients while they are in vulnerable situations, and to include and prepare important others to decide, if the person cannot speak for her- or himself.

It is thus time for the first international overview on evidence and experiences, programmes and perspectives on ACP around the world.

## Method

In order to find national opinion leaders and ACP practitioner champions of countries that were not represented in the ACP-i board during the time of preparing this overview, we contacted keynote speakers of previous ACP conferences and the upcoming ACP-i conference in Singapore, as well as authors of highly relevant papers on ACP research and implementation and asked them to invite ACP researchers or practitioners from other countries who could contribute. Based on the concept of the Special Issue on SDM, we prepared the following (non-comprehensive, non-obligatory) checklist of topics considered relevant to describe ACP concepts, frameworks, research, and practice of national experiences in ACP:

- *Background of the healthcare system* (short description and potential advantages and disadvantages for ACP implementation)
- *Policy or legislative efforts/milestones* to foster ACP implementation into the national healthcare system (From AD to ACP)
- *Definition(s) and model(s) of ACP used*
- *Groups addressed* (healthy, chronically ill, severely ill patients, children, persons incapable of decision making, psychiatric patients, pregnant women after prenatal diagnoses...)
- *Education/training of health care professionals and non-health care professionals in ACP*
- *Information materials used, documentation and digitalization of ACP processes in the healthcare sector and beyond*
- *Examples of institutional and community implementation*
- *Research agenda on ACP?;* Any budget set apart in the research programming on ACP
- *Patient and public involvement* (patient movement) in research and development of ACP
- *Addressing diversity and vulnerabilities* (cultural social) regarding ACP access and use
- *Main challenges and barriers*
- *Collaborations with other countries/programmes regarding ACP*

## Results

In the first call, authors from 25 countries including UK were invited, and all accepted to prepare a national report, with all four nations of UK (England, Wales, Northern Ireland, Scotland) separately contributing and providing a combined summary. Via the snowball method, we received three further national reports. In total, 28 countries, across all continents except Antarctica, contributed national reports that were peer-reviewed, edited, and accepted after minor or major revisions [19–46]. The editorial team

also received, reviewed and accepted a survey on attitudes, experiences, and implementation of ACP in Sub Saharan Africa [47], with feedback from practitioners from eight additional countries (Malawi, Ghana, Sierra Leone, Sudan, Cameroon, Kenya, Togo, Tanzania) (see Table 1). We further received a narrative review on the important topic of the content of the “ACP pill”, which was separately reviewed according to standard criteria of the journal and has been included in this Special Issue [48].

## Discussion

The theme of the 8th International ACP conference in Singapore was “ACP in Cultural Diversity: More Similar than Different” which is a similar conclusion one can draw from this first global report on ACP. ACP is considered as one of the key tenets of person-centered care, as shared decision-making for defining future goals of care and caring. However, we note that in many reports, ACP is described as limited to severely or even terminally ill patients “at the end of life”, as a process to prepare for anticipable events due to the illness trajectory, rather than defining goals of care also for unforeseeable events such as stroke or sudden cardiac arrest in otherwise healthy persons. Despite some focusing on ACP preparing for end-of-life care, many reported that ACP should be fostered upstream: as a commitment not only of the healthcare system, but of societies and “caring communities”, in which social workers, artists, volunteers and all citizens support and share what matters most to individuals, their families and the extended wider community of important others (such as the Maori whānau in Aotearoa/New Zealand [46]). One striking new insight is that although many authors from global east and the African and South American continent discussed the necessity to adapt the “individualized notion of autonomy” of the “western world” of ACP to their own more family-centred cultural contexts, many western countries also reported facing the same challenges such as the taboo of talking about death and dying, and the lack of communication skills in health care professionals. Indeed, globally, ACP is considered as being based in values of relational rather than individual autonomy only.

Context specific “cultural” – regional adaptation and variation, occurring in many (e.g. Switzerland [38]), but not all countries (e.g. Thailand [31]) seems to be a two-edged sword: On the one hand, cultural/regional adaptations of ACP are reported to be very helpful to meet the needs of populations. On the other hand, oversensitivity to variations within one country or region may lead to fragmentation, confusion about definitions and lower quality of ACP.

The legal system plays an important role in national ACP implementation. In general, laws and jurisdictions, strengthening the rights of patients to set up advance directives, especially if not limited to treatment in “terminal” or “vegetative state” situations only, and supporting surrogate decision-makers, are considered helpful or even necessary to implement ACP e.g. in Poland [42]. Yet, there are countries such as Norway [45] with ACP activities but no such legislation, and others, where legislation may have negative effects, for example in Australia [37] where each state has its own legal requirements regarding advance directives and surrogate decision-making, leading to fragmentation.

ACP continues to evolve as a global endeavor for delivering high quality health, social and spiritual care. There is a bundle of valuable insights we can share among us – and “us” is not only the scientific community but devoted society members. We hope that this first global report on ACP can serve as an energy boost for the long journey towards implementation and accessibility of ACP for all persons and populations, an equal opportunity to define what matters, for when it matters and to those who matter most to

**Table 1**  
Summary of country reports sorted by continents.

Continent/Country	Essentials	Ref
<b>Africa</b>		
Sub Saharan Africa	In a survey of health care professionals of 37 countries from Sub-Saharan Africa (practitioners of 9 countries responded) most had heard of ACP, 40% reported to have treated patients with ACP and almost all would respect one. Although this study uses a convenience sample, findings suggest that ACP is more widely respected in many African countries than is often assumed.	[47]
Rwanda	After the devastating genocide in 1994, Rwanda has made great progress restoring its healthcare system while palliative care and ACP are considered important these aspects of care are still in their infancy. Reflections on ACP and first implementation efforts include the importance of a culturally sensitive approach, which pays heed to the lessons learned in other countries.	[19]
South Africa	Despite huge challenges of social injustice, poverty, high death tolls, pressing needs regarding palliative care, and a low level of trust in the public healthcare system, ACP is evolving thorough policies, education and research by health care professionals and non-governmental organizations. Culturally sensitive ACP strategies are important to meet the needs of the population.	[20]
Uganda	Despite lacking a legal framework and structured processes for ACP, this mixed method study shows that ACP is highly appreciated and has become part of regular palliative care practice among palliative care physicians treating patients with advanced cancer in Uganda. National frameworks and increased public awareness are paramount for a sustainable implementation of ACP.	[21]
<b>The Americas</b>		
Canada	Canada has been one of the pioneers of ACP with a national strategy and framework in place for more than 15 years, promoting collaborations between professionals, communities, organizations, and the public. Priorities on the national, provincial, and local level are described, with ACP as an upstream life-long endeavor being the overarching vision of ACP Canada.	[22]
Brazil	To implement ACP as a patient-centered care concept in Brazil is facing many challenges due to social injustice, a paternalistic medical and judicial system and serious access barriers to palliative care, whose proponents are one of the pioneers of ACP in Brazil. ACP may therefore be misunderstood and misused as a tool to ration necessary care in vulnerable populations.	[23]
Argentina	Argentina has been paving the way for ACP for more than 20 years through laws, policy development, education and research on advance directives and implementation of ACP via national initiatives cooperating internationally with other Spanish speaking countries. Main barriers are lacking communication and cooperation skills in a still paternalistic medical culture.	[24]
Ecuador	Despite recommendations from the National Bioethics Commission in support of ACP, there is currently no legislation and only very few advance directives have been documented. In cooperation with international researchers (esp. Spain), an academic hub and the Ecuadorean palliative care movement intensely engage in ACP research and implementation.	[25]
United States	ACP continues to grow in the US, despite systemic barriers related to a fragmented healthcare system. Numerous innovations and resources exist to support ACP, though research on implementation as well as identification of person-centred outcomes is needed to move the field forward.	[26]
<b>Asia</b>		
India	The Indian Supreme Court has recently enabled advance medical directives (AMD). Implementation of advance care planning (ACP) will depend on civil society and the palliative care sector until government support is available. The description is based on a narrative review of the landscape and the Indian roadmap on ACP.	[27]
South Korea	Based on societal developments and a new legislation on life-sustaining treatment in 2018, ACP is gaining momentum in South Korea, an “ageing society” in which talking about death and dying has been traditionally a topic not very openly discussed. The National Agency for Management of Life-Sustaining Treatment plays an important role in education and implementation.	[28]
Philippines	Despite attempts to provide a nationwide legal base for advance directives and initiatives to foster ACP, which have been strengthened in the COVID-19 pandemic, there is no legislation or national framework in the Philippines. ACP is promoted by palliative care organizations, via national and international conferences and teaching ACP relevant skills.	[29]
Japan	Promoting advance care planning (ACP) in the super-aged society of Japan has become increasingly important for supporting older adults, despite legal barriers with regard to forgo life-sustaining treatment, and a traditional habit to not tell the truth. A national framework is in place since 2022, and the Health Ministry fosters training research and implementation on a national level.	[30]
Thailand	In the last few years, based on legislation in the 00er years fostering the rights of patients to write an advance directive and appoint a surrogate decision maker, which was first rejected by physicians, patients and their families, ACP implementation has made huge progress, with a national framework, standard documentation, training professionals and implementation.	[31]
Hong Kong	Although there is no legal framework supporting advance directives in Hong Kong, ACP has been successfully fostered by professional initiatives and hospital policy frameworks during the past two decades. Public awareness and training health care professionals including the use multi-media means have been successful as first steps to a nationwide ACP program.	[32]
Indonesia	Although Indonesia is a low middle income country with a diverse population and a chronically underfunded healthcare system, recent advocacy initiatives promise some hopes in ACP in Indonesia. Furthermore, local studies suggested opportunities to implement ACP, particularly through capacity building and culturally sensitive approaches.	[33]
Singapore	In 2011, a national programme in ACP was launched, backed by rather unspecific legal frameworks, growing and evolving over the last decade. ACP has become routine in some hospital units, challenges remain in implementing ACP as a standard of care across all levels of the healthcare system.	[34]
Malaysia	Despite a lack of a legal framework, of strong initiatives at a national level, and medical codes limiting patient autonomy and family input on decision making in serious illness Malaysia makes progress on ACP through implementation at an institutional level, through educational programmes as well as research activities.	[35]
Taiwan	Based on two legal frameworks on palliative care and patient right to autonomy, ACP is understood as the right of persons to set up advance decisions to withdraw treatment in case of terminal illness and severe neurological damage, after undergoing ACP conversations with health care professionals, having been trained in ACP. To broaden the scope is one of the main challenges.	[36]

(continued on next page)

Table 1 (continued)

Continent/Country	Essentials	Ref
<b>Australia</b> Australia	Australia is one of the pioneers of ACP, with a national ACP program based on the Victorian ACP program, and various recent developments. Nationwide initiatives include resources for training of professionals, quality assessment and support of the public, main challenges are (too many) initiatives fragmenting the system and inconsistent legal frameworks across states.	[37]
<b>Europe</b> Switzerland	Since 2013, advance directives are legally binding in Switzerland and ACP has been researched and implemented primarily by universities and university hospitals. Despite several national initiatives, professional organizations, and a roadmap for a national implementation, challenges and barriers remain, but the chance to implement high quality ACP in Switzerland is reasonable.	[38]
Belgium	Belgium has a strong ACP and palliative care movement, including an ACP relevant legislation (Patient's Right Law) since 2002, also including the possibility to ask for euthanasia in specific circumstances in an advance directive. Despite many initiatives, according to the small survey undertaken for the review, challenges remain (e.g. focus on documentation instead of communication).	[39]
Germany	Based on successful projects in the 00er years, Germany has passed a health care law allowing remuneration of ACP, yet limited to institutionalized persons (e.g. nursing homes). A national professional organization and research projects foster high quality ACP, however barriers include e.g. the lack of training and implementation, especially beyond the population targeted in law.	[40]
Netherlands	ACP has been and is intensively researched, based on an open view on patient autonomy and discussing death and dying in the legal and healthcare system, building on a strong General Practice sector. However, ACP has not yet been systematically implemented. Lacking communication skills and national implementation strategies are considered as barriers, currently being tackled.	[41]
Poland	Although first ACP models were developed decades ago, and there is a high degree of development and integration of palliative care, Poland is still a country where ACP has not yet been implemented. There is no specific legal framework and although committed health care professionals foster ACP individually, there is much room for improvement.	[42]
Spain	Following the establishment of a legal framework in 2002 and Delphi conferences on ACP in 2017, Spain has conceptualized ACP as shared decision making and patient centered care, focusing on frail, chronically, severely, and terminally ill patients. A national organization was founded in 2020, promoting the implementation of ACP that is not yet 'mainstream' across the healthcare system.	[43]
United Kingdom (England, Wales, Northern Ireland, Scotland)	UK nations have been one of the pioneers of ACP, rooted in a 40 year long legal and cultural history. ACP is considered as a concept to deliver person-centered care and mainstream national policy. Although there are considerable differences with regard to terms, processes, means, and implementation, all nations consider ACP as best practice not only for persons at the end of their lives.	[44]
Norway	Although Norway is a rich country, embracing person centered care, there is no legislation on advance directives and ACP has only recently been introduced. It has recently received increased attention from policy-makers and healthcare services with regard to research and implementation as a whole system approach that puts emphasis on the ACP conversation rather than documentation.	[45]
<b>Oceania</b> New Zealand/Aotearoa	The successful ACP programme in Aotearoa New Zealand is guided by the core values of a nationwide strategy. It has developed education, tools and resources to support consumers, whānau – the Maori extended family – and clinicians to optimise the opportunities for what matters most to a person to guide and inform care delivery throughout their life.	[46]

oneself, and thus support “personalized” health and social care in its true meaning worldwide.

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## Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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