# ARTICLE IN PRESS

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) xxx (xxxx) xxx

FISEVIER

Contents lists available at ScienceDirect

# Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ)

journal homepage: http://www.elsevier.com/locate/zefq



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

Advance Care Planning in Switzerland: Chances and challenges of delivering high-quality ACP in a small high-income, multilingual, federally organized country

Advance Care Planning in der Schweiz: Chancen und Herausforderungen der Implementierung eines hochwertigen ACP in einem kleinen, mehrsprachigen, föderal organisierten Land mit hohem Einkommen

Christine Clavien <sup>a,1</sup>, Ulrike Ehlers <sup>b,1</sup>, Ralf Jox <sup>c,1</sup>, Isabelle Karzig <sup>d,1</sup>, Tanja Krones <sup>d,1,\*</sup>, Barbara Loupatzatzis <sup>e,1</sup>, Settimio Monteverde <sup>d,1</sup>, Gudrun Theile <sup>d,1</sup>

- <sup>a</sup> University of Geneva, Geneva, Switzerland
- <sup>b</sup> Saint Gallen Cantonal Hospital, Saint Gallen, Switzerland
- <sup>c</sup> University of Lausanne, Lausanne, Switzerland
- <sup>d</sup> University Hospital Zurich, Zurich, Switzerland
- <sup>e</sup> Healthcare Trust Zurcher Oberland Wetzikon Hospital, Wetzikon, Switzerland

#### ARTICLE INFO

# Article History:

Received: 11 April 2023

Received in revised form: 19 April 2023

Accepted: 24 April 2023 Available online: xxxx

#### Keywords:

Advance Care Planning Shared decision-making

Peri-interventional Advance Care Planning

Switzerland

#### ABSTRACT

We describe the development of ACP in Switzerland during the last decade in the German- and French-speaking cantons and on the national level. In 2013, a revision of the Swiss civil law came into force, declaring advance directives (ADs) as binding. Since then, ACP has been researched and implemented primarily by universities and university hospitals. Despite the foundation of the national association "ACP Swiss" in 2020, several national initiatives, and a roadmap for a national implementation, many challenges and barriers still remain. There is, however, reasonable hope to implement high-quality ACP throughout Switzerland within the next ten years.

# ARTIKEL INFO

#### Artikel-Historie:

Eingegangen: 11. April 2023 Revision eingegangen: 19. April 2023 Akzeptiert: 24. April 2023

Online gestellt: xxxx

# $Schl \"{u}ssel w\"{o}rter:$

Advance Care Planning Partizipative Entscheidungsfindung

Periinterventionelles Advance Care Planning

Schweiz

#### ZUSAMMENFASSUNG

Wir beschreiben die Entwicklung von Advance Care Planning (ACP) in den letzten zehn Jahren in den deutsch- und französischsprachigen Kantonen der Schweiz sowie auf nationaler Ebene. Im Jahr 2013 trat in der Schweiz eine Gesetzesrevision in Kraft, die Patientenverfügungen für verbindlich erklärte. Seitdem wurde ACP primär in Universitäten und Universitätsspitälern beforscht und implementiert. Ungeachtet der Gründung des nationalen Vereins ACP Swiss im Jahr 2020, verschiedener Schweizweiter Initiativen und einer Roadmap für die nationale Implementierung bleiben viele Herausforderungen und Barrieren bestehen. Es gibt jedoch begründete Hoffnung, dass innerhalb der nächsten zehn Jahre ein qualitativ hochwertiges ACP in der Schweiz implementiert werden kann.

https://doi.org/10.1016/j.zefq.2023.04.008

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Please cite this article as: C. Clavien, U. Ehlers, R. Jox et al., Advance Care Planning in Switzerland: Chances and challenges of delivering high-quality ACP in a small high-income, multilingual, federally organized country, Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ), https://doi.org/10.1016/j.zefq.2023.04.008

<sup>\*</sup> Corresponding author. Tanja Krones. University Hospital, University of Zurich, Werk G 8, Rämistrasse 100, 8091, Switzerland. F-Mail: tanja krones@usz.ch (T. Krones)

<sup>&</sup>lt;sup>1</sup> The authors are in alphabetic order and have all contributed equally to the article.

# Introducing Switzerland and the Swiss health care system

Switzerland is a small, multilingual country in the middle of Europe, but not forming part of the European Union, with approximately nine million inhabitants, a high average income and high perceived quality of life [1]. The health care system aiming at universal health coverage (UHC) is rooted in the cooperation between different actors at the federal, regional (called "cantonal") and municipal level. Its logic focuses both on "individual responsibility and community solidarity" [2]. However, obligatory health insurance premiums do not differentiate between high- and lowincome inhabitants, which leads to about 40% of the population depending on subsidies for affording the increasingly rising insurance premiums [3]. In addition, Switzerland has the highest rate of out-of-pocket healthcare expenditures per capita among OECD-countries [4]. Several thousands of patients are only entitled to emergency care in some cantons due to a law enacted in 2012, allowing cantons to put patients on "blacklists" who have not paid the insurance fee. Thus, although Switzerland is formally committed to UHC [5], this goal is partially reached [6]. Palliative and nursing home care is only partly financed by the solidarity principle, resulting in a rank of 15 overall and regarding affordability a rank of 18 in the "Quality of Death index" [7]. The health care system is very decentralized. The 26 states, called cantons, have a considerable legal and executive power and freedom to form their regional health care system and set their priorities, and as Switzerland is a direct democracy, citizens have their own say in shaping it through the structures of democratic deliberation.

#### Legal background

Up to 2013, there was no national law regarding rights of persons temporarily or permanently incapable of decision-making. In a national survey conducted in 2010, only about 10% of the population above 75 years of age had advance directives (ADs) [8]. The legal situation changed with a national law enacted in 2013, declaring ADs as binding in all cantons, with only very few formal requirements [9]. According to this law, called "adult and children protection law", everyone has a surrogate with a formal hierarchy: The patient-designated surrogate ranks first, followed by courtappointed guardians with decisional authority on healthcare matters, then relatives or other persons living together with the currently incapacitated person. Only in the last instance, blood relatives (like adult children, parents or siblings) are taken into account, and only under the condition that they verifiably care for the person. Importantly, in this ranking, biological kinship is given significantly less weight than the lived social relationship when legal representatives have to be assigned. In the last decade, awareness of the importance of ADs and knowledge on ACP have definitely grown among both healthcare professionals and the general population [10–11].

Besides the legal changes, research as well as patient and professional organisation initiatives played an important role in the development of ACP in our country.

# ACP implementation: From ADs and research into ACP practice

In Switzerland, there is a considerable tradition of public, non-profit and private organizations who consider the provision of AD forms as a way of public engagement assumed to be of great benefit to the population and also as a "marketing" opportunity for the organisation and its values. Among them figure professional boards, patient organisations, but also banks, lawyers, politicians, right-to-die associations, religious communities, and local or regional health care institutions. Although some patient organisations and

regional initiatives recommended and supplied facilitation and support for persons who wanted to plan ahead, the concept of ACP was for a long time neither known nor discussed, even among health care professionals and their organisations. This changed with the national research programme on end of life funded by the Swiss National Science Foundation (2012-2017) [12], supporting several studies that investigated advance directives and advance care planning. In what follows, we describe in a chronological way, the most important advances made in practice and research on ACP.

# Major ACP implementation projects launched in the Germanspeaking part of Switzerland

The most prominent project at that time [13] that directly drew on international evidence-based, person-centred ACP programs [14–16] was the randomized controlled MAPS trial (Multiprofessional Advance care Planning and Shared decision making for end of life care), focussing on severely ill hospitalized patients and their surrogates. ACP was significantly superior to standards of care regarding most primary and secondary endpoints in this trial.

Already during the MAPS trial, which was expanded from the hospital trial to a pilot nursing home study [17], elements of the ACP intervention were implemented and further developed not only in the canton of Zurich and the University hospital of Zurich, where the trial was conducted, but spread to other cantons, institutions and organisations in research and implementation projects. Several hundred professionals in the German speaking region have received training in ACP facilitation. A large project initiated during the second phase of the MAPS trial was the "ACP-NOPA" project [18]. The project was triggered by the needs of a group of palliative care specialists for individualized emergency plans. Soon after the beginning of the discussion with the MAPS trial team, it became clear that "foreseen emergencies based on the underlying illness" is not the only concept in which individualization makes sense. but the expectation of the patient concerning his/her future treatment – the individual goal of care of each patient. The current ACP-NOPA-Web application supports professional caregivers in conducting an ACP conversation, creating an AD based on goals of care and shared decision making including an "ÄNO" (ärztliche Notfallanordnung), an adaptation of the POLST (Physician/Portable order for Life sustaining treatment) to translate both in a concrete treatment planning and future treatment planning for the individual patient's case based on his/her case history (Fig. 1).

Parallel to the development of the ACP-NOPA web application, a continuous medical educational program for interprofessional specialized palliative care teams was developed. It focuses on enhancing communication skills concerning ACP discussions, prognostic awareness via the Serious Illness Conversation guide as well as palliative treatment planning with simulated patients and practical exercises in the use of the Web application. After the ACP-NOPA-Web application was successfully implemented working with palliative patients in and out of hospital the program was expanded to include chronically ill hospitalized patients to prepare for discharge, as well as ambulatory chronically ill patients to prepare for a sudden deterioration and emergencies, and specific emergencies in cardiac patients with devices (left ventricular device, defibrillator).

For in-hospital applications, a peri-interventional ACP tool was developed in order to discuss and document emergency goals of care on the ward, before, during, and after surgery or interventions ("Hospital POLST") in alignment with patient's preferences expressed verbally, in ADs or presumed wishes expressed by surrogates (Appendix A). A "one pager" to inform nurses and physicians

underlying illness						.616.	
☑ Tumor □ H	leart	☐ Lung			lanning	a Wating about	
tumor				medizinisch	i begleitet. ®	palliative zh+sh	
Primary tumor  Brain  ENT  Lung  Abdomen  Metastases  Brain  Lung  Abdomen  Musculoskeletal  Mamma				Emergency Plan for KH - 27.03.1950  POLST-E: Therapeutic goal – Prolonging life, but with the following limitations  No cardio-pulmonary resuscitation (no CPR) Otherwise, unlimited emergency and intensive care treatment			
☐ Hematological system							
Diagnoses (important diagnoses which should be seen on the emergency plan)  Pancreatic cancer				Emergency Numbers Please call the numbers below if there is no improvement after the application of the proposed measures  Palliative Team, Palliative Care Team: Tel. Palliative Arzt, Tel.			
				Emergency	What to do?		Emergency medication
Save Possible emergency situations				no reaction, no breathing	do NOT call 144 emergency num	! stay calm hold hands and watch call aber	
Present Medication				Dyspnoe	once, if symptor the emergency hospitalization.	take emergency medikation for Dyspnoe ms are not getting better after 30 min: call number (see above). Decision about Take living will with you. Jung bei Eintritt mitnehmen	Morphin Tropfen 2 % 2-5 gtt max. once/hour
Medication already in use (only medication that can be used for emergency)	Suchen nac	Acetalgin 1g; 1 bis max 3 Tbl täglich Acetalgin 500 mg; 1 bis max 6 Tbl täglich	Pain	getting better a	medication for pain if symptoms are not ofter 2 hrs: call the emergency number (see n about hospitalisation. Take living will with	Novalgin 0.5g/ml gtt max. 4x 30/ daily Morphin Tropfen 2 % 2-5 gtt max. once/hour	
	☐ Actiq 160	Actiq 1600 mcg; 1 L Actiq 200 mcg; 1 Lu	icg; 1 Lutscher max stdL wiederholen icg; 1 Lutscher, max stdL wiederholen g; 1 Lutscher, max sdtl wiederholen g; 1 Lutscher max stdl wiederholen	Nausea, vomiting	(expanded Abde vomiting, audib number immedi	medication if there are signs for ileus omen, abdominal pain, no defecation, ale peristaltiv sounds): call the emergency lately, hospitalization for darification. Take you. If no defecation for 3 days, take constipation	Motilium sublingual 10mg Tbl max. 3 Tbl/daily
		Actiq 600 mcg; 1 Lutscher max stdl wiederholen Actiq 800 mcg; 1 Lutscher max stdl wiederholen Aldactone 100 mg Tbl Aldactone 25 mg Tbl	desorientation, agitation		r medication call the emergency number cision about hospitalisation. Take living will	Haldol 2mg/ml gtt max. 3x5/daily     Temesta 1mg exp Tbl max. 5/daily	
		Aldactone 50 mg To Bricanyl Inh Spray;		Date:		Name	Signature:

**Figure 1.** Examples of the template for entering the underlying illness (pancreatic cancer with metastases in the abdomen) and emergency medication (left side) as well as the proposal of an emergency plan created by the ACP-NOPA-Web application (right side) based on an individualized (emergency) life prolonging goal of care excluding resuscitation.

how to discuss the "Hospital POLST", is also included in the one-day ACP –NOPA Training for physicians.

The «Hospital POLST» was already in use in a paper version during the COVID -19 peaks and was primarily used for discussing and documenting preferences of elective high-risk patients (e.g., before pulmonary endarterectomy or organ transplantation) in case of major surgery and possible complications during and after interventions. For every intensive care (ICU) patient, the therapy goal should be defined from the beginning so that the treatment plan can be adjusted accordingly [19]. Elective high-risk patients who have been offered peri-interventional ACP now form a subgroup of intensive care patients whose personal care goals are significantly better known than patients entering as unplanned "emergency admission". In patients without previous ACP, care goals are often first discussed with their substitute decision maker when a sometimes foreseeable, complication or prolonged treatment in the intensive care unit occurs. A valid AD is of course also binding for intensive care physicians since 2013 (see introductory section), provided it is feasible and reasonable [20].

Yet, most patients who enter the ICU - foreseeably or as an unforeseen emergency - still do not have an AD or have one that is not integrated into their care due to administrative reasons in the hospital [21–23]. In these cases, all intensive medical life-prolonging measures are primarily carried out until the necessary information can be obtained, as delivered by the surrogate decision maker. If there is none, according to the Swiss law, as described above, a person is determined according to the surrogacy hierarchy and the goals of care and patient's presumed wishes are intensely and often many times discussed, which shows the importance of high-quality communication skills of ICU physicians.

# Major ACP projects in the French-speaking part of Switzerland

In 2016, the newly established Chair in Geriatric Palliative Care at Lausanne University Hospital in Western, French-speaking Switzerland started to launch a series of research projects on ACP. One preliminary initiative was to find an appropriate and commonly used French translation for the term ACP, since multiple incoherent and clumsy translations are used in French-speaking counties [24]. This conceptual work, done in collaboration with researchers and practitioners from Geneva, concluded with the suggested terminology "ProSA" ("Projet de Soins Anticipés"), which has recently been adopted by the national roadmap described below [25]. Moreover, capitalizing on a strategic collaboration between researchers in Lausanne and Zurich, the MAPS trial ACP documents were translated from German to French and adapted to the cultural specificities of the French-speaking region.

The first empirical research project in Lausanne was called "Alzheimer's Disease-specific Intervention on Advance care planning (ADIA)" [26]. Although the dementia-specific ACP model was feasible and accepted by patients and relatives, there were significant methodological challenges related to the regional culture, such as gate keeping by paternalistic physicians who were skeptical of ACP or a reluctancy in disclosing the diagnosis of dementia to patients, as well as the wide-held belief that having checked a brief advance directive form once would be sufficient and obviate the need to engage in ACP [27].

A second research focus in Lausanne is ACP *by proxy*, given the observation that a large portion of the older population has already lost decision-making capacity without having engaged in ACP and that ACP by proxy has been described as common practice in other countries [28–29]. Based on an explorative study in the long-term care homes underscoring the need, a specific ACP by proxy model was developed for this population, including trained ACP

facilitators among leading nurses in four long-term care homes and specific documentation and guidance for ACP by proxy.

In addition to these research projects, there has been a considerate effort over the last five years to implement an ACP facilitator training in the canton auf Vaud with its capital Lausanne, a population of 800,000 people. This has been made possible by the bilingual ACP-certified facilitators who have been educated in an ACP train-the-trainer course. To date, more than 60 facilitators have been certified in the French-speaking canton of Vaud, mostly coming from palliative care, geriatric care, long-term care homes and social work in health care. These certification courses as well as a networking activity among the various healthcare stakeholders in the region has been financially supported by the cantonal Ministry of Health that is convinced by the necessity of ACP in its health care sector.

ACP is also promoted in the Geneva region, another Frenchspeaking part of Switzerland. The HUG (Geneva University Hospital) plays a leading role in this process. The strategy deployed since 2021 is complementary but different to what is done in other parts of the country: provide basic training to all health professionals and facilitate ACP discussion and documentation with help of digital and communication tools. At the HUG all professionals (physicians and nurses) follow a short basic mandatory ACP e-learning in which they learn the basic concepts, reasons, and ways to conduct ACP discussions with patients, how to document and update patients' goals of care and to discuss and update emergency medical instructions when a patient's health state changes significantly. Moreover, tools have been developed to support these ACP discussions [30]. A digital tool, named "Accordons-nous", is freely available on the HUG smartphone app [31], designed to be used by patients and their relatives independently at home, or in support of discussions with health professionals. Nurses and physicians in different hospital units (oncology, nephrology, palliative care) are explicitly invited to use the app "Accordons-nous" and its included card game "Anticip'action" (also available in paper format) when discussing goals of care with their patients [32]. The general aim is to change the professional culture towards ACP and empowerment of patients.

# National consensus and (dis)agreements, chances, challenges and barriers

In parallel to the strong impact of research projects in various regions of Switzerland on regional implementations, several national initiatives and implementation of ACP have been launched during the last ten years.

In 2017, a new curriculum for medical students came into force, based on the Canadian curriculum, which now entails general objectives (GO) and entrustable professional activities (EPAs) with regard to ACP (e.g. EPA 7.6 Understand and apply the concept and basic elements of Advance Care Planning; EPA 7.16 Prescribe measures for treatment of pain, palliative and end-of-life care, taking into account any advance directives or a "do not resuscitate" request [33]). ACP is also increasingly taught and assessed in undergraduate nursing education. Based on a first national ACP framework (see below), the ACP initiatives in Lausanne and Zurich further developed the continuing education program for ACP facilitators, and fostered the ACP-NOPA web tool (see above) for documenting the ACP process in an AD, including the "ÄNo"

On behalf of the Federal Office of Public Health [34], from 2017 to 2018, an interprofessional working group developed a framework concept for the implementation of ACP in Switzerland based on a scoping literature review as well as national and international experiences. The framework concept was intended as a basis for concretizing and coordinating further steps. In its revision of the

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medical-ethical guidelines on death and dying, the Swiss Academy of Medical Sciences introduced for the first time the concept of ACP in the guidelines framework [35]. These guidelines were also formally adopted by the Swiss Nurses' Association and recommended to its members. In the perspective of the guidelines, written documents following the logic of ACP are considered as a genuine expression of shared decision-making and goals of care in the context of incurable illness. However, there is only scant information about the ACP process itself.

# **Impacts of COVID-19**

Also in Switzerland, the Covid-19 pandemic has increased the public awareness not only about the importance of fostering serious illness conversations, but also about knowing and documenting the person's will when it comes to assigning critically scarce medical resources [36]. During the first phase of the pandemic, in which elderly and chronically ill persons in particular had to reckon with a severe course of the disease, the meaningfulness of differentiating ADs moved into the awareness not only of the affected population groups, but also of the medical professional societies. Some organizations drafted documents specifically addressing the situation of ventilatory therapy as a result of Sars-CoV 2, which were to be used on their own or as a supplement to an existing AD. As a result, there was a new rethinking of previous forms of ADs. The discussions within experts and professional societies were intense, controversial and ultimately served as an impetus for the revision of widely used documents such as the AD of the Swiss Medical Association (FMH), the overarching association of Swiss physicians. The huge demand and need of valid ADs promoted the founding of the national organisation ACP Swiss, with its aim to foster high quality Advance care planning in 2020 [37] based on research and experiences in Switzerland. The new medical-ethical guidelines on cardiopulmonary resuscitation, published in 2021, regularly refer to the importance of ACP, yet without further specification on tools or skills [38].

# **Current national developments**

Triggered by the results of the above-mentioned National Science Foundation research projects and the first national framework on ACP, published in 2018, in the same year, a postulate by a committee of the Council of States called for "better care and treatment of people at the end of life," which led to a report by the Federal Council. This report on "Improving the conditions for the treatment and care of people at the end of life" [39] was published in 2020. The Federal Council proposed measures to implement ACP in Switzerland. One of the measures was to establish a permanent national working group with a leadership assigned to the Bundesamt für Gesundheit (BAG) and the Swiss Academy of Medical Sciences, including representatives from health politics, physician and (patient) organizations promoting ADs, hospitals, members of ACP Swiss and from ACP research projects. Rather than science-based working procedures, the group follows a political democratic procedure with expert consultation. As a result, the "roadmap" recently published by the group [25] remains vague regarding the very concept of ACP. It includes generally formulated recommendations, addressed to patients, relatives, and interested parties and professionals, for raising awareness, providing information, improving quality of AD forms, clarifying and harmonizing medical emergency orders, enhancing teaching of professional communication competencies, and establishing a framework for payment of services. In the light of international concepts of ACP, this roadmap can be considered a step forward as a "minimal consensus" in a federalist country. In the future, as subgroups will be formed on different areas of ACP implementation, there are reasonable chances to integrate evidence-based results as well as high quality national and international experiences into the future discussion and decision process.

In this paper, we have illustrated the complexity faced by our country which is organized in a multitude of fairly independent administrative and political units, with their own web of medical care structures and patient organizations. Improvement of ACP at the country level still needs important efforts to involve and convince all stakeholders, at the scientific, medical, administrative, and political level.

#### **Conflict of Interest**

We hereby declare, that all authors of the article have received honorariums for talks and/or teaching of Advance Care Planning. No other Conflicts of Interests.

# **CRediT author statement**

All authors have contributed equally to the writing and edition of the article.

- T. Krones has primarily conceptualized the article. She received funding for conducting research on and implementation of Advance Care Planning by the Swiss National Science Foundation (SNF), the Bundesamt für Gesundheit (Bern), and the Canton of Zurich (Innovation pool).
- R.J. Jox has written parts of the article and reviewed the last version. He received funding From Alzheimer Schweiz the Spicher Foundation and the SAMW.
- C. Clavien has written parts of the article and reviewed the last version. She has received funding from the Foundation of the Hospital de Geneve for the development of the Accordons-nous app and the e learning.
- I. Karzig has written parts of the article and reviewed the last version. She received funding for conducting research on and implementation of Advance Care Planning by the Swiss National Science Foundation (SNF), the Bundesamt für Gesundheit (Bern), and the Canton of Zurich.
- U. Ehlers has written parts of the article and reviewed the last version.
- G. Theile has written parts of the article and reviewed the last version.
- B. Loupatatzis has written parts of the article and reviewed the last version. She received funding for conducting research on and implementation of Advance Care Planning by the Swiss National Science Foundation (SNF), the Bundesamt für Gesundheit (Bern), and the Canton of Zurich.

# Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.zefq.2023.04.008.

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