

HEALTHY AGEING IN THE FACE OF DEATH

Advance Care Planning Dialogue Workshop 27-28 March 2023

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10 years of advance directives in Switzerland:
an interdisciplinary public health perspective on advance care planning

Abstract Book

March 27, 2023

Session 1: Introduction to the end of life and end-of-life care planning in Switzerland

Anthropological perspective on the end of life in Switzerland

Marc-Antoine Berthod

University of Applied Sciences and Arts Western Switzerland (HETSL | HES-SO)

In Switzerland, as elsewhere, the fact of dying and especially of knowing how one dies has attracted the attention not only of public health authorities but also of health care personnel and researchers from a wide variety of disciplines. Over the last forty years, this interest has been progressively strengthened with the aim of anticipating and accompanying the ageing of the population and the development of professional and institutional management of this particular time. This focus on the 'end of life', a term that has now become established in the literature and public policies, nevertheless denotes a significant paradigm shift from an anthropological point of view on the theme of death: to put it schematically, what matters now is less a question of the dead and funeral rituals - of death in all its materiality - than of the configurations of dying and its biological, psychological, social and spiritual components. Accordingly, it is important above all to understand the individual whose death is 'reasonably foreseeable' in terms of his or her personal, cultural and social environment, while identifying the role and limits of the professionals who intervene with the patient and his or her loved ones, particularly through advance directives and advance care planning. This presentation therefore aims to put into perspective the emergence of this particular time of 'end of life' and the forms of anticipation that underlie it. It first traces some historical, cultural and social trends that allow us to understand this shift in focus from death to dying, and then suggests some avenues for reflection on contemporary models of 'good death' and, by contrast, on the risks of 'bad death'. For in the end, the ways of anticipating the 'end of life' say something about the relationship that our contemporary societies maintain with death and the dead.

Knowledge from the NRP 67 "End of Life"

Markus Zimmermann

University of Fribourg, Switzerland

The research-phase of the NRP 67 "End of life" lasted from 2012 until 2017. As past-president of the steering committee I was asked to give an overview of the ACP-research that was done during that time. Although only one of totally 33 research projects of the NRP 67 was dedicated to ACP, it's a pleasure for me to answer to that question in a first part by giving an overview of what was done by Tanja Krones and her team in Zurich: They conducted a randomized control-trial – patients at the end of their lives with and without ACP – and published main results in 2019. Despite of their enormous efforts, real evidence on the effectiveness of ACP is still questioned. I'll secondly go into some further developments in the field of ACP research and politics in Switzerland. Thirdly I'll formulate some tricky questions concerning the idea of ACP, as they were debated controversially e.g. in a workshop on "Challenges and opportunities of ACP" in the USA or as they arise by looking at personal experiences. One observation is that ACP should resolve two quite different problems while discussions deal often only with one of them: Potential patients should express their wishes and preferences concerning their (end of) life, while care-givers suffer pressure to make difficult clinical end of life-decisions that should be eased. The question is whether, and if so, how, personal wishes can be translated into clinical decisions. Perhaps it could be fruitful to seek societal

consensus on meaningful dying processes and encouraging physicians to act in that direction, rather than to motivate each individual to make his or her personal choices. The “Value of Death Study” (Lancet 2022) could probably bring up new ideas by admitting: “Dying in the 21st century is a story of paradox. Although many people are overtreated in hospitals, still more remain undertreated, dying of preventable conditions and without access to basic pain relief.”

Understanding end-of-life care planning decisions in older adults living in Switzerland

Sarah Vilpert

HEC, University of Lausanne

The law on advance directives (ADs) was introduced into the Swiss Civil Code in 2013. ADs allow for the expression of acceptance or refusal of medical treatment in case of loss of decision-making capacity. It is recommended that adults of all ages and health conditions complete one. In the context of our research project « Healthy ageing in the face of death », we are investigating how ADs are understood, perceived, and accepted in a nationally representative sample of older adults living in Switzerland shortly after the introduction of ADs into law (2015) and four years later (2019). To explore factors associated with AD behavior, we draw on behavioral theories and use data from the Survey of Health, Aging and Retirement in Europe (SHARE). This presentation will provide an overview of the results of this research project. It will also show how this information is relevant for public health stakeholders to improve the process of advance care planning in the general population and to define corresponding programs.

Session 2: ACP in medical and nursing fields

Ethical rationale and essential elements of ACP

Ralf J. Jox

Institut des humanités en médecine, CHUV-UNIL

In this presentation I will highlight the shortcomings of the traditional approach to advance directives in medical practice and present the ethical rationale and the essential elements of any advance care planning model, according to scientific evidence and the recommendations of ACP Swiss.

The role of anticipatory planning and ACP in Palliative Care in Switzerland

Steffen Eychmüller

Center for Palliative Care, University Hospital Bern, Inselspital

ACP has become a trendy word in health care in Switzerland. The federal office of public health initiated a first taskforce in 2016, and a second in 2021 in order to develop a national framework on this topic. During both working groups, Palliative Care experts were involved because of the frequent clinical situations confronted with patients wishes and preferences at the end of life. Several questions emerge: when is the best time to start anticipatory planning? Formulating a patient's advance directive and defining a patient representative – should this be everyone's duty throughout the entire life – and not only if a severe illness changes life expectancy? In addition, palliative care frequently develops care plans for emergency situations if illness progresses: is this part of ACP which yields on patients not being able to decide any more, or is this kind of anticipatory planning for emergency situations something different? These questions will be further discussed during the workshop.

Advanced Care Planning from a Nursing perspective

Catarina Letras

Clinica di Cure Palliative e di Supporto - IOSI-EOC, Bellinzona - Ticino

An Advanced Care Planning (ACP) process can be complex and difficult to sustain for people who want to undertake it, especially if they are chronically ill.

There is, however, evidence that nurses play a key role in accompanying these patients and supporting them in their choices, as they are central to their care and usually have known them for quite some time (especially in long-term facilities). Nurses can, in fact, understand when to start a dialogue about ACP with the patient and play an important role in the counselling process in relation to the patient and his social network, thanks to a constant communication with them.

Nurses with an advanced clinical practice (i.e.: Advanced Practice Nurses) and a specific training, can also play a crucial role in implementing an ACP process within their organisations, together with an interdisciplinary team, thanks to their education and clinical expertise.

Session 3: Experiences of care services with ACP

ACP in hospital practice

Claudia Gamondi

Service de soins palliatifs et de support- CHUV

Patients are often in acute situations, with multiple needs and symptoms, sometimes with acute or chronic cognitive impairment. In an ideal world, ACP should be discussed outside these critical moments of the illness trajectory. In real life, professionals working in hospital settings are often confronted with the need to take critical life decisions with patients that are not well known to them and often in emergencies. A further complexity is represented by the fact that a few percentage of the population have completed advance directives and so very often in hospital settings, professionals cannot count on this instrument of self-determination. In modern medicine, a shared decision making model is recommended and it is advisable that clinicians do their best to maximize patient's informed autonomy. For these reasons, professionals working in hospitals and especially those working in palliative care are used to offer ACP to patients and support those who choose to draft advance directives documents. Specific training and competencies are required to present ACP to patients while confronted with acute suffering and a high symptom burden, to include their values and wishes in daily care and to foster open communication concerning realistic possibilities of care, prognosis and incertitude.

ACP in home care and nursing home practice

Eve Rubli Truchard

Chaire de soins palliatifs gériatriques, CHUV

Residents in nursing home are the target population to identify their wishes in case of future medical problems, since the majority of them will use the health care system in the same year and will even die within two or three years. Entry into nursing home often occurs in a crisis context, following an unwanted hospitalization, and an entry into nursing home that was not completely desired. In addition, the prevalence of cognitive impairment makes discussions about their health preferences more difficult. Discussions about ACP do not necessarily go through the resident, but often directly through the family members, and thus respecting the resident's presumed wishes is a challenge for the health care professionals involved. The time available to nursing home professionals and training for these discussions are challenges, as is the transmission of and respect for the documentation if there is a hospitalization.

Ideally, discussions should take place in the patient's home, prior to admission to a nursing home. Here is an example of a typical home consultation by a specialized nurse practitioner from the geriatric service of the CHUV, who intervenes at home, for elderly people with complex needs, who are followed by the multidisciplinary ambulatory geriatric consultation. Being able to take this time in the patient's home, in several sessions, in a non-acute context is a real advantage. The issue of funding for home-based ACP and the political will to promote these discussions is a current challenge.

GPs - key persons in the field of ACP – what role will they play in the healthcare landscape of the future?

Klaus Bally

Universitäres Zentrum für Hausarztmedizin beider Basel

GPs have an important role in the context of ACP. Elderly people in particular consult their GPs with a certain regularity; the majority of people have a long-standing relationship with their GPs based on trust. GPs are acquainted with the presenting health conditions, the family environment and often the values and needs of their patients. Therefore, GPs are also expected to inform their patients about opportunities and benefits of ACP or to engage in ACP advice and support. In addition, GPs are often consulted when treatment decisions are under discussion.

Dealing with ADs / ACP is an integral part of the Swiss Catalogue of Learning Objectives for Undergraduate Medical Training since 2008, with the addition that it is a particularly relevant problem for General Practice and Outpatient Medicine. To date, there is no national recommendation or consensus on the extent to which GPs should be involved in ACP.

2/3 of all GPs in Switzerland consider themselves rather or very confident in handling with ADs and fully agree with the statement that ADs are an essential aid for end-of-life decision making. The majority of GPs in Switzerland use short pre-printed AD-forms in which a surrogate decision maker is named and also consent or refusal to essential life-prolonging measures is documented. GPs consider the creation of an AD as an occasion for an in-depth conversation about values and wishes. In the majority of all cases, patients take the initiative to create an AD, only in 1/3 of the cases GPs take the initiative.

Barriers for engaging in ACP are for GPs time constraints, lack of skills to deal with patients' vague requests, difficulties with defining the right moment, and fear of depriving patients of hope. Facilitators are the long-standing relationship, appropriate skills in ACP advice, competence in anticipating problems during disease, and knowledge of who should be integrated into the ACP process.

The development of the Swiss healthcare system, the expected number of practicing physicians, the remuneration of medical advice in general practice and the offer of further training opportunities for ACP interested GPs will point the way for the future commitment of GPs in the area of ACP.

Session 4: Psychological and cultural approach of ACP

First comes thought. Planning ahead of a loss of decision-making capacity

Francesca Bosisio

HEIG-VD

Advance directives emerged in the 1960s with the goal of empowering people to exert control over their future medical decisions. However, it has become apparent, over recent years, that advance directives do not sufficiently capture the temporal and relational aspects of planning treatment

and care. Advance care planning (ACP) has been suggested as a way to emphasise communication between the patient, their surrogate decision maker and healthcare professionals in order to anticipate healthcare decisions in the event that the patient loses decision-making capacity, either temporarily or permanently. In Switzerland though neither advance directives nor advance care planning raised to their potential of preventing people to receive care that is inconsistent with their needs and preferences. In this talk we will contextualise and examine what are motivations and barriers to advance directives and advance care planning and sketch a few ways forward to support people and professionals in planning ahead of a loss of decision-making capacity.

Promouvoir les Directives anticipées par le Théâtre - « J'ai pas fini » ou le Formulaire : 2016 – 2018

Eric Masserey

Médecin cantonal Valais

Origine du projet en 2015 : puisque la population connaît insuffisamment les Directives Anticipées (DA), il faut les promouvoir. Mais comment ?

A l'Office du médecin cantonal vaudois, l'idée de produire une énième brochure a ennuyé tout le monde, les réseaux sociaux n'ont pas paru un outil privilégié pour accéder à la population cible, plutôt âgée, les médias sont difficiles à solliciter en dehors d'un événement... il fallait donc créer l'événement. Un collaborateur a lancé, un peu pour rire, la proposition d'en faire une pièce de théâtre. Acceptée sur le principe, la pièce de théâtre a été financée par la Santé publique et la Fondation Leenaards.

Les DA au théâtre convoquent le tragi-comique sur scène, entre Iris, une femme pré-soixantaine, traumatisée par les circonstances du décès de sa sœur, et son jeune assureur Maxime qui lui propose un rabais sur ses primes si elle rédige ses DA. Leur discussion sera sans cesse bousculée par le formulaire de l'Académie Suisse des Sciences Médicales, et les tentatives de Maxime pour avancer dans les réponses. Iris n'est pas préparée au vertige que suscite chaque question, fondamentale, essentielle, éminemment complexe. Que dire et comment le dire ?

La pièce de théâtre, professionnelle, à quatre comédiens, créée en novembre 2016, a eu un impact médiatique considérable, a fait la une de plusieurs journaux, a été présentée par différentes radios, le téléjournal. Elle a été représentée une vingtaine de fois pendant un an et demi dans de nombreux lieux de Suisse romande.

Session 5: Cultural differences in ACP in Switzerland

Regional disparities in advance directive completion in older adults living in Switzerland

Maud Wiczorek

LIVES, University of Lausanne

A previous work by Vilpert and colleagues reported that in 2015, older adults from French- and Italian-speaking Switzerland were considerably less likely than adults from German-speaking Switzerland to have completed advance directives (ADs). The present study aimed to assess whether the regional disparities in AD completion observed in 2015 persisted over time and to identify the factors that may explain these regional disparities.

We used data from wave 6 (2015) and wave 8 (2019/2020) of the Survey of Health, Ageing and Retirement in Europe (SHARE) in Switzerland. AD adoption was defined as not having completed ADs in wave 6 while having completed ADs four years later. We first checked the robustness of the association between the region of residence and AD adoption by including pre-selected socio-demographic, health, attitudinal characteristics, and factors related to interactions with the

healthcare system in different statistical models. Secondly, we attempted to decompose the contributions of each of the pre-selected factors in the regional differences in AD adoption. Overall, 30.1% of respondents reported the completion of ADs between 2015 and 2019/2020. The proportion of AD adoption was much higher among respondents living in German-speaking Switzerland, compared to respondents living in French- and Italian-speaking Switzerland (37.1% vs 14.4%, respectively). The association between living in German-speaking Switzerland and a higher probability of AD adoption remained significant when including all other respondents' characteristics in the models. Additional analyses revealed that 11% of the regional disparities could be attributable to the different distribution in the socio-demographic, health-related, attitudinal characteristics and factors related to the interaction with the healthcare system between regions, suggesting that other meso- or macro-level factors may play a role in these disparities.

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Keynote speaker:

A public health approach to advance care planning

Joachim Cohen

End-of-Life Care Research Group, Vrije Universiteit Brussel

Abstract coming

Session 7: FOPH/SAMW project on ACP

Outcomes of the ACP working group coordinated by the FOPH and SAMW

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Outcomes of the Advance Care Planning (ACP) Working Group coordinated by the Federal Office of Public Health (FOPH) and the Swiss Academy of Medical Sciences (SAMS)

Advance health planning promotes self-determination. It should be accessible and understandable to all who wish to engage with it. There is potential for improvement in Switzerland. For that reason, in its report on Postulate 18.3384 "Better care and treatment of people at the end of life", the Federal Council, mandated the FOPH and the SAMS to set up a joint working group 'advance care planning' (ACP WG) in May 2021. The ACP WG consists of experts from the fields of medicine, nursing, palliative care, social work, law, and ethics. Also represented are national professional associations, organisations of healthcare providers as well as patient and stakeholder organisations that offer consultation on the subject. The task of the ACP WG is to develop a framework to strengthen and firmly establish advance care planning in the health system in Switzerland.

The ACP WG devised a model with modules and specific recommendations for this purpose. This model underwent a broad public consultation. The input received has been incorporated in a "Roadmap for the implementation of advance care planning in Switzerland". A strength of this approach is that it is based on a shared understanding of the needs and of the measures to be promoted. The Roadmap answers the questions 'who, when, what and how' around advance care planning and formulates twelve recommendations. The latter target any individual interested in

ACP (e.g. Define and notify a healthcare proxy), and the professionals (e.g. foster communication skills and knowledge), and address quality issues (e.g. minimal quality standards for advance directives forms).

The Roadmap is the first step, albeit an important one, in a process. Much work lays ahead in order to achieve concrete results. It is the basis for implementation of specific projects and work. Sub-groups with relevant expertise will be set up and given mandates. It is planned to set up working sub-groups dedicated to specific issues.

Session 8: Spiritual aspects of ACP and individuals' healthcare competences

Spiritual support in ACP

Etienne Rochat

Institut des humanités en médecine, CHUV-UNIL

In the first part, after a brief review of the "ACP and spirituality" theme, we will share some examples of how the health system and health care institutions use religious and spiritual resources to concretize, but without thinking it, the orchestration of dying and death. We will show how chaplains or spiritual caregivers, in this sense, are pioneers of ACP.

In a second part, we will answer three questions to define and understand the links between "ACP and spirituality" following: Why is ACP so important today in the context of modern medicine? What model of comprehensive care should be used to include ACP and spirituality? How can consideration of the person's spirituality facilitate the development and implementation of ACP and what are the challenges that emerge when clinicians practice it?

In the third part, we will sketch out some avenues for the future. First, we show how the evolution of the health care system requires us to take an interest in the theme of spirituality in a new way, especially if the latter has the ambition to carry out ACP. Second, by setting out some of the conditions of possibility for doing research in this field, in particular to get out of the epistemological and clinical impasses in which this research is currently mired.

Importance of end-of-life health literacy and knowledge in care planning among older adults

Clément Meier

FBM and HEC, University of Lausanne

Individuals' attitudes toward advance care planning (ACP) can be influenced by their health literacy and knowledge of the topic. Health literacy skills influence how people perceive their health difficulties, communicate with healthcare providers, and make medical decisions. Knowledge regarding end-of-life medical situations is likely to shape individuals' decisions to engage in ACP. This study investigates the associations between individuals' end-of-life health literacy and knowledge and their attitudes toward end-of-life care planning among a representative sample of adults aged 58+ in Switzerland.

We used data from 1,369 respondents from wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe. Subjective end-of-life health literacy was measured with questions on the competencies in understanding medical interventions, finding information, communicating, and making decisions about end-of-life care options. Respondents' knowledge was assessed using test-based questions on 11 end-of-life medical situations. Engagement in end-of-life care planning was measured by having advance directives (ADs) and/or having designated a healthcare proxy and approving to have ADs in the future. Associations were estimated using separate probit regressions, controlling for social, health, and regional characteristics.

We found that respondents with higher end-of-life health literacy tended to have higher end-of-life knowledge. Individuals with higher end-of-life health literacy were also more likely to approve and have ADs. Individuals with higher knowledge scores were more likely to have completed ADs. Finally, when we simultaneously included both variables in the model, only the positive association of end-of-life health literacy with approval and completion of ADs remained statistically significant. Our findings show that end-of-life health literacy seems to play a preponderant role in ADs approval and completion. Thus, encouraging the writing of ADs should not be based exclusively on informing individuals but should focus on strengthening their competencies to complete ADs by providing them with adequate support.

Session 9: Support and promotion of ACP

Swiss Red Cross - Advance directives

Nathalie Gerber & Hubert Kausch

Swiss Red Cross

Advance Care Planning (ACP) enables people to take account of their personal values with respect to health and illness. The Swiss Red Cross (SRC) offers comprehensive support in drafting and depositing a valid advance directive (AD). Coming to terms with future potentialities is easier as part of a discussion. Therefore, the SRC service comprises a dialogue. The offer includes regional consultations on the establishment of ADs. The specially trained SRC counsellors have all the knowledge necessary. During the consultation, the SRC supports people to make self-determined and well-informed decisions. Thanks to the SRC depository, an AD can be transmitted to the relevant medical staff 365 days a year, around the clock, and is available as a complete document for decision-making.

The SRC has been dealing with the issue of ACP in the form of the ADs since 2005, i.e. long before the introduction of the new adult protection law. Besides providing a document available in German, French and Italian, the focus has always been on advising people who want to make an AD. Special attention was and is given to people who are less accustomed to writing and learning or who are not native speakers of one of the national languages. With the introduction of the adult protection law, the range of services has been standardized and expanded nationally.

The SRC reaches people outside of institutions, who personally have little experience of illness but who are aware of cases among people they know. In view of their relatives, they want to take responsibility for possible difficult decisions in the future. This offer strengthens the resources of these people, so that they are well prepared for a specific life situation that leaves them highly vulnerable, such as an incapacity to judge and /or at the end of life.

Challenges include the financing of the entire offer and making the public aware of it.

Advance Care Planning (ACP) implementation in the Canton of Vaud

Robin Reber

Réseau Santé Région Lausanne

The Advance Care Planning (ACP)¹, is a discussion process between a specifically trained professional, called a "facilitator," a patient and his or her relatives. The aim of this process is to accompany the patient in a reflection on his or her values and preferences in order to enable him or her to express his or her goals of care and anticipated measures in the event of a life-threatening

¹ Translated « Projet de Soins Anticipé » (ProSA) in French

emergency and/or incapacity of discernment. It is therefore a matter of developing health partnerships and supporting patient self-determination

The Réseau Santé Région Lausanne (RSRL) is a health network that brings together regional health actors (nursing homes, home care services, hospitals, etc.) In 2017, some members of the network proposed to adapt the ACP approach to the canton of Vaud context. The RSRL has therefore started a collaborative project with representatives of its members; this is articulated in three phases: an inventory carried out in 2018², a design and testing phase³ (2018-2021) and finally a pilot implementation phase (2020-2022).

The deployment of the ProSA in the Canton of Vaud is continuing thanks to a partnership between the Réseau Santé Région Lausanne, the Chair of Palliative Care (UNIL/CHUV) and Espace Compétences SA with the support of the State of Vaud. A training course has been set up that has already trained 86 professionals in ProSA support, demonstrating the growing interest in it. Communication tools (including presentation video, website⁴, e-learning package and leaflet) have been developed in order to raise awareness of ProSA and support its practice. Moreover, the RSRL supports the deployment of ProSA within the structures of the Canton of Vaud wishing to implement it through meetings, feedback from the field as well as the organization, in partnership with the CSPG, of exchange platforms between professionals practicing ProSA.

The deployment of ProSA raises two main issues:

1. Systemic issue: providing care consistent with patients' wishes does not depend solely on increasing the frequency of ProSA but also on:

- Systematically and purposefully informing professionals, the public, patients and their relatives about the tools for anticipatory decision making in anticipation of loss of capacity for discernment;
- Move away from a vision that is limited to organizing care around the patient and value partnership and interprofessionality; indeed, interprofessionality is a prerequisite for the realization of the care partnership, and is consubstantial with clinical governance projects such as the ProSA;
- Improve the transmission of information throughout the patient's clinical pathway: the patient's wishes and advance directives must be known and accessible when needed.

2. Structural issue: most of the ProSA process' steps are already carried out today in scattered or unstructured activities. In this respect, ProSA is still very often perceived as an additional task in an already stretched care routine. One of the main barriers to its adoption is the lack of financial incentives. The process takes an average of 4-5 hours and several strategies are being experienced today in order to integrate ProSA as a transformation of chronic care practices that can at least partly be carried out within the existing financial framework, and to find additional resources to support the conditions of its realization.

Despite these challenges, the ACP approach continues to develop in the Canton of Vaud, carried in particular by a growing community of professionals convinced of the benefits of this approach, and an increasing demand in the general population.

² Lila Devaux, Mathilde Chinet, France Nicolas, et Philippe Anhorn, « Le Projet anticipé des soins (PAS), Un PAS du Réseau vers l'autodétermination des patients, Phase 1 : Etat des lieux », *Réseau Santé Région Lausanne*, 2018.

³ Robin Reber, Lila Devaux, Mathilde Chinet, Patrick Martino, Alban Ridet et Philippe Anhorn « Le projet de soins anticipé (ProSA), Test d'implantation dans trois structures de soins du Canton de Vaud » *Réseau Santé Région Lausanne*, 2021.

⁴ <https://www.projetdesoinsanticipe.ch>

Smartphone app Accordons-nous: concept, use and impact

Christine Clavien

Université de Genève

We have developed Accordons-nous, an ACP digital tool freely available in the HUG app Concerto (<https://concerto.hug.ch/applications>). This tool informs patients about advance care planning, facilitates communication on these sensitive topics, and helps patients express their priorities, their preferences for care, and write their advance directives. In this talk, I will present the concept, the use and the impact of Accordons-nous.