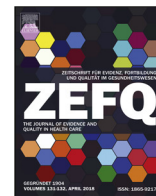




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Advance Care Planning in Spain

Advance Care Planning in Spanien

Cristina Lasmarías^{a,*}, Virginia Carrero^b, Júlía Fernández-Bueno^c, Helena García-Llana^d, Nani Granero-Moya^e, Javier Júdez^f, Núria Pérez de Lucas^g, Iñaki Saralegui^h, Tayra Velascoⁱ

^a Research Nursing at the Catalan Institute of Oncology, Barcelona, Spain

^b Dept. of Educational, Developmental, Social and Methodological Psychology in the Faculty of Health Science at the University of Jaume I of Castellón, Castelló de la Plana, Spain

^c Palliative Care Hospital Team, Hospital de la Princesa, Health Public Service, Madrid, Spain

^d Psychology Department, Centro de Estudios Superiores Cardenal Cisneros (Universidad Complutense de Madrid), UNIR, Universidad Pontificia de Comillas, Madrid, Spain

^e Nursing Department, Faculty of Health Sciences, University of Jaén, Jaén, Spain

^f Instituto Murciano de Investigación Biosanitaria Pascual Parrilla (IMIB), Servicio Murciano de Salud, Murcia, Spain

^g Palliative Care Home Team, Health Public Service, Madrid, Spain

^h Palliative Care Unit, OSI Araba, Osakidetza, Spain

ⁱ Bioethics and Nursing Department, Faculty of Health Sciences, Universidad Complutense de Madrid, Madrid, Spain

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ABSTRACT

In the last decade in Spain, an important push has been given to the development of health policies that define the framework of action in the care of people with advanced chronic diseases. Respect for the autonomy of the patient, shared decision-making processes and advance care planning (ACP) are recognized into health plans as a key aspect in chronic care, frailty, and palliative care. A few but significant number of institutions, local governments, and healthcare professionals from different regions of Spain have started a rationale and roadmap for a new twist in Spain's theoretical, ethical and policy development, promoting ACP implementation into public health care systems. In 2020, a working group founded in 2017, evolved into the "Spanish Association of Shared Care Planning" (AEPCA). The Shared Care Planning (SCP) concept grows up after the two international consensus Delphi studies in 2017 and pretends to shift from the framework of ACP programs to a person-centred care approach. In the last years, several experiences show how professionals are more sensible and interested on the ACP process, but it cannot be said, for now, that it has taken effect in the global Spanish health system. Even both ACP and SCP are being used simultaneously in Spain, each day more people and autonomous communities embrace renewed concept and foundations of SCP, supporting the work of AEPCA on spreading the value of this process into the care of people who are coping with chronic diseases, vulnerability, and frailty.

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ZUSAMMENFASSUNG

In den letzten zehn Jahren hat die spanische Gesundheitspolitik, die den Handlungsrahmen für die Gesundheitsversorgung von Menschen mit fortgeschrittenen chronischen Krankheiten festlegt, einen enormen Schub erhalten. In den Gesundheitsplänen wird der Achtung der Patientenautonomie, gemeinsamen Entscheidungsfindungsprozessen und einer vorausschauenden Gesundheitsplanung (Advance Care Planning, ACP) eine Schlüsselrolle für die Versorgung von chronisch kranken, von gebrechlichen und von Palliativpatient:innen zuerkannt. Einige wenige, aber bedeutende Institutionen, Kommunalverwaltungen und Gesundheitsfachkräfte aus verschiedenen spanischen Landesteilen haben Argumente und einen Fahrplan für eine neue Wende in der theoretischen, ethischen und politischen Ausrichtung Spaniens erarbeitet, um die Implementierung von ACP im öffentlichen Gesundheitssystem voranzutreiben. Aus einer 2017 gegründeten Arbeitsgruppe ging im Jahr 2020 die Asociación Española de Planificación Compartida de la Atención (AEPCA) hervor, die „Spanische Vereinigung für gemeinsame

* Corresponding author. Cristina Lasmarías, PhD. Head of Nursing Research at the Catalan Institute of Oncology, Av. Gran Via de l'Hospitalet 199-203/08908 L'Hospitalet, Barcelona, Spain.

E-Mail: clasmarias@iconcologia.net (C. Lasmarías).

gesundheitliche Versorgungsplanung“. Das Konzept einer gemeinsamen gesundheitlichen Versorgungsplanung (Shared Care Planning, SCP) entstand im Gefolge zweier internationaler Delphi-Konsensusstudien im Jahr 2017; damit wird eine Verschiebung von den herkömmlichen ACP-Programmen hin zu einem personenzentrierten Versorgungsansatz angestrebt. In den letzten Jahren haben verschiedene Erfahrungen gezeigt, dass das Bewusstsein und das Interesse für den ACP-Prozess auf Seiten der Gesundheitsfachkräfte zwar zugenommen haben, noch kann aber keine Rede davon sein, dass dies im spanischen Gesundheitswesen insgesamt schon wirksam geworden wäre. Auch wenn ACP und SCP in Spanien derzeit parallel bestehen, machen tagtäglich immer mehr Menschen und autonome Gemeinschaften von diesem neuen Konzept und den SCP-Grundideen Gebrauch und unterstützen dadurch die AEPCA in ihren Bemühungen, den Nutzen dieses Prozesses auch in die Pflege von chronisch kranken, vulnerablen und gebrechlichen Menschen hineinzutragen.

Background of the healthcare system

Spain is a developed country with a population of approximately 47 million inhabitants. It has a national health system that provides universal health coverage (except in some circumstances), offering free assistance at all levels of care: hospital, intermediate and community. Since 1986, authority over health policy began to be progressively transferred to the 17 autonomous communities, which is how the different regions of the country with their own autonomous government are referred to (Ceuta and Melilla are excluded, which have a model of government dependent on the central government) [1]. Each autonomous community defines its own health plans and manages health resources, but they receive financial items from the central government that are part of the state budget. This decentralized health management system enables local management and access to health resources, based on the needs of each autonomous community, but leads to great variability in the development of health policies that entail situations of inequity, as is the case of development of advance care planning (ACP).

In the last decade in Spain, an important push has been given to the development of health policies that define the framework of action in the care of people with advanced chronic diseases. Chronic care, especially advanced chronic care and in frail older people, are the great challenges of the Spanish public healthcare system [2]. Despite the fact that primary care in Spain is the backbone of its healthcare system, in practice, care for this group of people with a disease continues to be carried out in a fragmented manner and focused on acute hospital care (despite the fact that close to 40% of people admitted to tertiary level hospitals have palliative care needs) [3].

An example of the diversity of health policies can be seen in the deployment of care plans in palliative care (PC). In 2001 the first National Palliative Care Plan was created and in 2007 the Palliative Care Strategy was developed, which sought to promote equity in the development of this discipline throughout the country [4]. However, in the last report prepared by this Strategy (2022), it is stated that only 4 of the autonomous communities meet all the indicators defined in the development of PC models and programs, and 14 (of the 17 autonomous communities plus Ceuta and Melilla) have some model or plan to address ACP [5]. But when analysing the detail, it is observed that many of them allude to the registration of advance directives, not specifically ACP.

Respect for the autonomy of the patient, shared decision-making processes and ACP are recognized as a key aspect in chronic care, frailty and palliative care, and this has been reflected in many regional health plans, both in relation to advance directives or ACP. However, the deployment of this process at the institutional level and in daily practice is very scarce and it cannot be said, for now, that it has taken effect in the Spanish health system.

Legislation on ACP: autonomy of patients

The exercise of autonomy of people in the field of health care has been legislated in Spain within the General Health Law in 1986 and, specifically, since 2002 based on a mandatory state law [6]. At the same time, all the autonomous communities developed their own legislation, and some have even enacted specific regional laws on rights and guarantees in end-of-life, palliative care or ACP. All these laws regulate the development of advance directive documents, their operational aspects, and the official electronic systems where these documents must be registered in order to be consulted [7]. Each autonomous community has its own advance directive documents registry, which in turn is transferred to the national registry. People can access advance directive documents, write them, and deposit them in the registry without having to share them with their health team. But they can also be deposited in the medical record and can be consulted by authorized health professionals. As of January 2023, there are 402,761 registered documents, which represents approximately 1% of the population (this % varies among autonomous communities).

If this data is taken into account, it can be concluded that the legislation on advance directives documents is not enough for citizens to express their wishes and that these can be respected in the event of not being able to communicate. Studies indicate some reasons for this failure: lack of proper training for health care professionals on the end of life, communication skills and advance directives; lack of a public process to increase awareness about advance directives, which has led to a great lack of knowledge among patients, and thus only certain groups especially sensitive to end of life issues (chronic and terminally ill patients, as well as their families, caregivers and certain ideological groups) are fully aware of them and registry properly; excessively cumbersome bureaucratic documentation and implementation procedures, which are a barrier for patients to prepare them and for professionals to consult them when necessary; the continued existence of a paternalistic medical culture, both among patients and health care professionals, which makes it difficult to reach shared decisions with patients and their relatives [8]. In addition, coinciding with the legislative development of the beginning of the 21st century, various people linked to the field of bioethics identified the need to export the Anglo-Saxon concept of ACP to our environment and, following the lead specifically of the United States, initially from a bioethical framework, and in the line of the process to decide in advance about medical treatments for situations of incapability of decision making [9].

From this approach, the works published throughout the first years of the 21st century reflect the effort to deepen the concept of ACP [10–11], but its definition tends to be based more on ethical-legal aspects, and less on the organizational and operational aspects of the process itself. This, in practice, is not enough. Somehow, the experience reflected in the United States from the SUPPORT study is replicated: the legislation and the ethical frame-

work, based on compliance with bioethical principles, without the communication process and the organizational bases, do not favour people seeing their wishes respected [12]. In this regard, the principle of autonomy is recognized as the ethical foundation of ACP. However, people state that participating in the decision-making process is important to them [13], and they want to do so in a relational context, which is known as a model of relational autonomy [14]. Therefore, it is pertinent and necessary to develop programs that respond to the concerns of people, enhance self-efficacy to the professionals, contemplate the care environment and fit into the care framework of the time. In other words, putting theory into practice. For this reason, the efforts of influence groups, such as the Spanish Association for Shared-Care Planning (AEPCA) believe that beyond specific legislation, developing ACP implementation programs in practice is necessary, especially on the state and later regional level, following the model of the deployment of palliative care plans.

Finally, the recent enactment of the euthanasia law recognizes the importance of planning as a tool in the deliberative process that is generated in response to a request for help in dying, and this is enabling the visibility of the ACP process as a tool for decision-making [15].

Despite this regulatory deployment, to date there is no specific state legislation on ACP, and therefore no national implementation strategy.

Definition(s) of ACP used

Considering what has been said above, some initiatives emerged to focus the understanding of ACP as a central person

and patient centered approach to elicit preferences regarding goals of care and medical treatments.

In 2017, the Spanish ACP working group was created, made up of expert professionals in palliative care, chronic care, and bioethics, and from professional fields of medicine, nursing, and psychology from parts of the national territory [14]. In the same year, two Delphi consensus studies had been published regarding the evolution of the concept of ACP, reflecting the focus on goal concordant care and a person centered approach [15–16]. Taking into account the agreed upon international definitions, the previous experiences of Spain, and the professional experience of the members of the group, was established to discuss how to use the Spanish National Health System strengths and merge the concept of shared decision-making (SDM) for current care decisions with the pursuit of ACP for future care. This approach was named “shared care planning” (SCP) and in 2020 the working group evolved into the “Spanish Association of Shared Care Planning” (AEPCA).

Shared Care Planning (SCP) is defined as: “deliberative, relational and structured process, which enables the consideration and understanding of the experience of disease and care among the people involved, focused on the person facing a disease trajectory, to identify and express their care preferences and expectations. Its goal is to promote shared decision-making in relation to the current context and future care challenges, such as those moments in which a person lacks the capacity to make decisions for her/himself.”

SCP is aimed at people with a chronic disease, regardless of the clinical context, but it can be understood in 3 different phases of the disease trajectory (see Figure 1). In each of these phases, various tasks or actions can be done that derive from the SCP process that must be related to the clinical trajectory, the phase of the disease and the individual needs of the person (see Table 1). It is especially

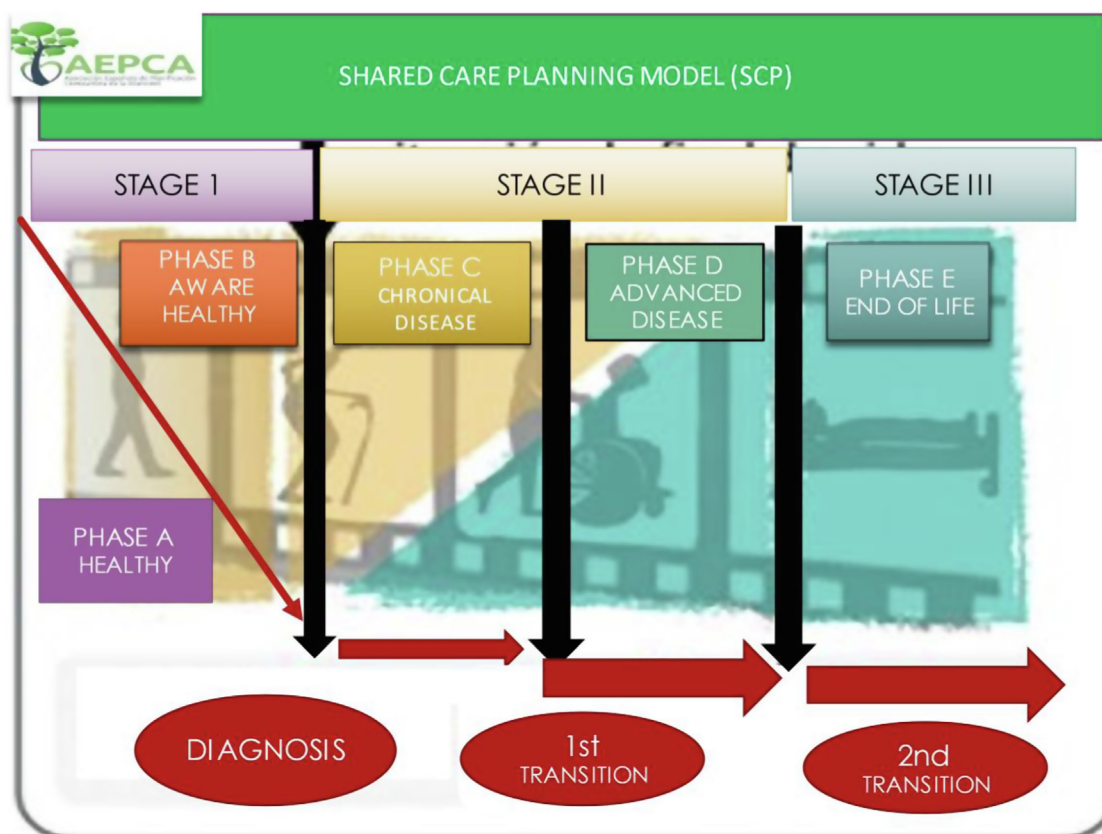


Figure 1. Shared Care Planning model developed by the Spanish Association of Shared Care Planning 2020.

Table 1
Shared Care Planning tasks according to the AEPCA proposal.

Tasks proposed by the Shared Care Planning				
PHASES	MAIN GOALS	INSTITUTION / PROFESSIONAL TASKS	TASKS ADDRESSED TO PATIENT	FACILITATING MATERIAL
PHASE A HEALTHY PATIENT	- To disseminate - To promote advance directives	- To provide information required	- To promote knowledge and awareness	- Brochures, flyers, websites
PHASE B AWAWARE HEALTHY PATIENT	- To respond to demands - To document and record the patient's preferences. - To promote Advance Directives documents	- To explore previous experiences and clinical settings - To document patient's preferences and to assign a legally entitled representative	- To foster personal awareness - To clarify doubts - To share with family and loved ones	- Interview outline - Advance Directives document registration
PHASE C CHRONICAL DISEASE	- To Initiate SCP process - To promote patient engagement - To involve family according to patient preferences	- To generate professional connection / welcoming with the patient - Diagnosis disclosure communication adapted to patient's needs. - To facilitate SCP registration/ systems to clinical records	- To promote reflection about the disease process - To be aware about diagnosis and prognosis - To be compliance with treatment.	- Interview outline adapted to the trajectory disease. - SPC registration Form - Conversation guides
PHASE D ADVANCED DISEASE	- Re-assess SPC in trigger situations. - To concrete clinical settings, wishes and preferences. - To identify dissonances	- To conduct in deep interview with family and loved ones. - To promote spiritual and existential approach - To manage hope reconceptualization	- To reflect on preferences and goals of care according to trajectory and prognosis	- Interview outline adapted to the trajectory disease. - SPC registration form - Conversation guides
PHASE E END OF LIFE	- To prevent complicated grief among family members and loved ones. - To adapt care interventions to the patient's choice preferences - To reduce/resolve dissonances	- To signify threats / resources - To provide continued care and support to the family - To facilitate a good dying	- To commit on Respecting choices and values - To guarantee accompanying family to facilitate the farewell to their loved ones	- Registration form

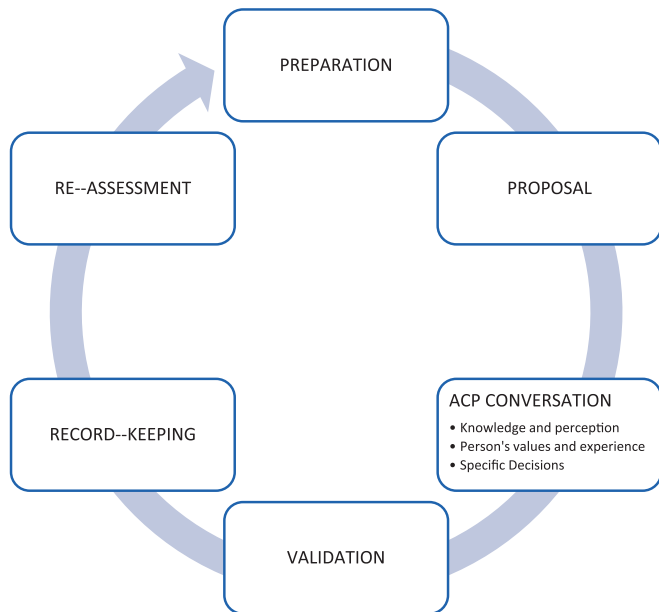


Figure 2. Advance Care Planning cycle according to the Catalan model.

relevant to offer it to those people who are at high risk of losing cognitive capacity, but not exclusively. Finally, it is understood that the encounters with the sick person can be prepared to be more efficient, and for this reason SCP is conceived as a cycle that is made up of 5 steps: 1) explore the patient's values and capacity; 2) shared decision-making; 3) document patient preferences; 4) review and update preferences; and 5) respect consensual decisions.

Groups addressed

The population susceptible to initiating SCP processes is one that meets the criteria of a complex chronic patient, an advanced chronic patient, or a person at high risk of losing cognitive capacity. However, as we have seen in the model proposed by AEPCA, based on tasks, incorporating actions of the SCP process starting with meetings with patients is suggested. This will enable the decision-making process as the disease progresses and clinical complications and uncertainty are more present.

Another sensitive population group is the one of people involved in the field of mental health, but, except for some very local guidelines (such as Andalusian and Catalan), there are no specific programs that reflect a model of care and ACP for people with mental disorders.

Examples of institutional and community implementation

There is currently no national ACP program in Spain. Given that the various regions of Spain define their own health policies, identifying how ACP is developing in each region is complicated. Most of the actions that have been implemented have been local initiatives, in some cases institutional (some hospitals, nursing homes), but usually the result of the initiative of some especially motivated professionals trained in the subject. However, there are some experiences that are worth highlighting.

The publication of the Andalusian Guide in 2013 [16] is one of the first references on the implementation of ACP in the field of health care. This guide is practical, offers concrete intervention guidelines, and is especially focused on the communication process as a basis for conducting the ACP process. In Andalusia, the Bioethics strategy contemplates as one of its objectives the promo-

tion of shared decision-making processes that allow citizens to identify and express their preferences and expectations of health care. Specifically, the strategy refers to actions aimed at developing a standardized and accessible clinical record within the health history, to create a network of professional facilitators in Primary Care centres for information, dissemination, training, awareness, and support for the ACP, among other initiatives. Moreover, the Andalusian School of Public Health carries out various activities aimed at Professionals from the Andalusian Public Health System that include specific training for ACP. More specifically, training in this regard is included in the University Diploma specializing in Bioethics, within the module "Ethics of the clinical relationship, capacity and decision-making" or in the courses "Advance planning of decisions in mental health" and "Advance Care Planning and Emotional Support at the End of Life".

In 2014 the development of the Catalan Model of ACP [17] was proposed in Catalonia, linked to the health plan aimed at caring for people with advanced chronic diseases. The model emphasizes the importance of primary care as the pillar of the ACP process, since it is considered to be the care profile that can best respond to the needs of people with frailty and chronic conditions. In this project, the conceptual framework and a practical guide of ACP was developed, which understands ACP as a cycle made up of 6 steps: 1) prepare the meeting; 2) ask permission; 3) start the dialogue; 4) validate the agreements; 5) register; and 6) re-evaluate (see Figure 2). A specific space was included for the registration of ACP in the medical records, and a 10-hour online training module was carried out that was offered to health professionals in the entire territory [18].

In the Basque Country, an institutional project aimed at citizens focused on advance directives [19] has been developed and came to be thanks to a local project led by a doctor trained as a facilitator in Respecting Choices® [20]. The project is based on providing conversations in the field of primary care and nursing homes for the elderly, the training of health and socio-health professionals, and the community outreach of the foundations and benefits offered by the participation of people in decision-making that affects their health. In addition, soon, the autonomous community of the Basque Country will publish the palliative care plan, which shows the SCP (they have incorporated the concept Shared Care Planning) as a key process to offer quality palliative care to people with advanced disease.

Although both proposals share values and promote the participation of sick people, one could say that the Basque model is committed to a community approach and that it arises from a bottom-up strategy (currently extended to the entire autonomous community) and the Catalan strategy provides a vision of a system based on a top-down strategy. At present, in the absence of specific indicators that make it possible to compare both models, it cannot be said which of the two strategies has been more successful.

Other initiatives worth mentioning: a research competitive projects in Bioethics such as "Kayrós-Conversations that matter" was carried out from the region of Murcia. The arduous progression from a single research project [23], unfolded between 2004-2014, to a regional reference program supporting the ACP plan of the Region of Murcia, developed in 2019, includes the result of a multi-professional and multidisciplinary regional Working Group with training of several hundreds of healthcare professionals with special grasp in palliative care, chronic care and professionals that support clinical ethics. In addition, the Kayros research experience has been reviewed in 2021 by one of Respecting Choices (RC) leaders, Linda Briggs, among the International Examples of adaptations of RC as "The Spanish adaptation" starting in 2004, as one that "represents the experiences of lone physicians, nurses, community advocates, and others who encountered the challenge of engaging their colleagues and healthcare professionals in the importance of ACP and figuring out how to disseminate its advantages." [21].

In 2022, the Community of Madrid has proposed a Decree regulating ACP, including this process as a right for all chronic patients [22]. It describes 4 phases: exploration of values and preferences, early decision making, documentation and registration in the clinic history, and review.

Both Murcia and Madrid plans have incorporated SCP concept instead of ACP within their health plans.

Finally, to date, there is no community experiences in relation to ACP. However, we consider that the recent enactment of the euthanasia law has caused concern regarding the issue of respect for the wishes and the right to decide of Spanish citizens.

Training for health and non-health professionals

There is no standard ACP training. There is also no national registry of training activities, and each autonomous community registers its own. This makes it difficult to assess the impact of ACP training being carried out in Spain. In Catalonia, for example, almost 6,000 professionals completed the online training included in the Catalan model of ACP. Awareness-raising workshops were also carried out in primary care and their perception of self-efficacy was evaluated after the implementation of the Catalan model [28]. In the Basque Country, more than 2000 primary care professionals have attended specific SCP courses.

The AEPCA has created various basic and advanced level training materials, designed for face-to-face and online formats, and which have been taught throughout almost all of Spain. After the pandemic, a Moodle AEPCA platform was created that enabled e-learning courses. So far, the AEPCA has trained approximately 300 professionals, belonging to almost all the autonomous communities. In October 2022, the first national conference of the AEPCA was held, which is intended to be held biannually. This association is beginning to be recognized as the great promoter of the concept of SCP in Spain [25], as well as becoming progressively more prominent in national training programs of family physicians [26].

Information Materials used into community programs

Most of the tools that have been developed for ACP or SCP promotion have been based on the Go Wish Cards program. This is the case with the Babespean cards, which were adapted to Spanish and reduced the number of cards [23]; or the Dodecahedron of Planning, which created a dodecahedral figure by transforming the messages of the letters into images, selecting the 12 that patients most commonly chose [24]. This figure won a few local awards for its originality and practicality.

Research and publications

To date, there are very few Spanish studies in relation to ACP. The Kayros project was funded with a national grant and the development of the Andalusian Guide was supported by research projects initially focused on advance directives documents.

The Spanish version of the consensus study by Rietjens et al. [27–28] was published in the year 2019. A self-efficacy scale in ACP has recently been validated [29] and the protocol for a clinical trial in patients with advanced heart disease has been published, results still pending [30]; there is also a line of research in cancer patients that has given few scientific results so far [31]. There are local initiatives in the form of research projects published in national journals [32–33], doctoral theses, final degree projects, master's projects.

From the Valencian community, the Health Faculty in the Jaume I University of Castellón and the Chronic and Long-Term

Care Hospital Paré Jofre in Valencia have developed a line of research that support the Interdisciplinary Health Team in planning the intervention in Advance Care Planning, taking into account the values, wishes and goals of patients/family. This line of research has been supported by public funds that have had as a main result the generation of an Intervention model based on Resignification processes in Advanced Chronic Disease and End of Life. Current research is focused to transfer tools created from those research projects as the “Needs Detection Tools for Advance Care Planning (IDENT-PAD Instrument); The Assessment of the Impact of the Advance Care Planning Process on the Interdisciplinary Health Team (PAD-IM Instrument) and Exploration of the Sources of Meaning at the End of Life [34]. All of them have not been yet published.

Without a doubt, the evaluation of ACP and SCP processes is one of the most significant improvement areas. The absence of evaluation indicators to assess national programs and adapted to our context makes it difficult to generate scientific evidence, but current initiatives suggest that in the coming years evidence will be generated in various areas.

Main Challenges and Barriers

The main barriers found in Spain at present are:

- Lack of homogeneity in the concept: although many autonomous communities have already integrated the concept of ACP, different acronyms are still employed when referring to planning (for this paper only 2 have been show, ACP and SCP). However, we believe that the meaning given in each definition shares the essence of the process: that the person feels informed, respected, and involved, in order to achieve their goals of care.
- Lack of institutional recognition: there are very few examples of healthcare or nursing home institutions that have incorporated spaces for the specific registration of ACP in medical records (Andalusia, Catalonia). This entails that the importance of the process in improving continuous patient care is not recognized, nor are specific spaces or health care professional's agenda contemplated to carry out the process.
- Lack of knowledge of professionals: the rejection of professionals is the main challenge, and at the same time it is the main task of associations such as AEPCA, which promote awareness and sensitivity of professionals through face-to-face and online training.
- Taboo when talking about death: the difficulty that professionals have when facing difficult conversations with patients is recognized, especially when talking about death [35,36], which is why initiating ACP processes is often controversial.
- New legislation: The recent enactment of the Law for the regulation of euthanasia has given a boost to ACP. The planning process is recognized as a key tool in deliberation with patients once they request help in dying. This has made professionals aware of the complexity of communication and deliberation processes and has raised the need for training in this regard.

Collaborations

The people who make up the AEPCA are regular teachers in various training programs in Latin America. Recently, an Argentine and an Ecuadorian work group have requested authorization and collaboration to culturally adapt the Advance care planning self-efficacy Spanish (ACP-SE Spanish) scale.

Conclusions

The ‘right to grant and register an advance directives’ has spread within Spain's health care legislation. The current reality is that documents are completed by less than 1% of the population. This reality does not sympathize with the way we human beings suffer, endure, and face illness. While this “administrative or contractual” approach remains stuck, a few but significant number of healthcare professionals from different regions of Spain have shared an intellectual journey and created a rationale and roadmap for a new twist in Spain's theoretical, ethical and policy development, promoting ACP implementation into public health care systems.

The challenges in conducting quality improvement and research studies are reflected in the national dialogue on the value of ACP and the importance of standardization in measuring the effectiveness of ACP interventions. And the SCP concept offers the opportunity to generalise a common understanding of ACP through the country.

Even both ACP and SCP are being used simultaneously in Spain, each day more people and autonomous communities embrace the renewed concept and foundations of SCP, supporting the work of AEPCA on spreading the value of this process into the care of people who are suffering chronic diseases and conditions, vulnerability and frailty.

Conflict of interest

The authors declare that there is no conflict of interest.

CRedit author statement

C.L. conceptualized the manuscript. C.L., J.J., I.S., T.V., N.G., J.F., N.P., H.G. and V.C. were involved in methodology and data collection. C.L. wrote the draft of the article. C.L., J.J., I.S., T.V., N.G., J.F., N.P., H.G. and V.C. reviewed and approved the final article. All authors have read and agreed to the published version of the manuscript.

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