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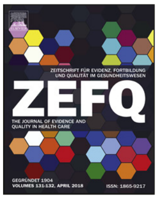

Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives“

How should Argentina raise Advance Care Planning awareness? Introduction of the Shared Care Planning Group

Wie kann das Bewusstsein für Advance Care Planning in Argentinien geschärft werden? Einführung der Shared-Care-Planungsgruppe

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ABSTRACT

The WHO Concept Model of Palliative Care emphasises empowering people and communities with Advance Care Planning (ACP). In Latin America, a more relational approach involving family members is suited to ACP. Improvements in doctor-patient-family relationships are needed. Policy efforts have been made to foster ACP in Argentina's healthcare system, but implementation barriers include a need for more communication skills and coordination between healthcare providers. The Shared Care Planning Group Argentina aims to promote ACP through research and training programs. It has sensitised and trained 236 healthcare providers in short courses to introduce basic information and skills. However, there needs to be specific documentation for ACP in Argentina. Research found obstacles to ACP implementation, such as the inability to converse with patients and the lack of coordination between healthcare teams. A new project will assess the self-efficacy of healthcare professionals who assist patients with Sclerosis Lateral Amyotrophic in ACP and evaluate a specific training program. Patient and public involvement in ACP remains limited in Argentina, with paternalistic medical culture and a need for more awareness and training among healthcare professionals as significant barriers. Collaborative research projects with Spain and Ecuador aim to train healthcare professionals and evaluate ACP implementation in other Latin American countries.

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ZUSAMMENFASSUNG

Das WHO-Konzept zur Palliativversorgung hebt darauf ab, Menschen und Gemeinschaften durch vorausschauende Gesundheitsplanung (Advance Care Planning, ACP) in ihrer Handlungskompetenz zu stärken. In Lateinamerika eignet sich für ACP ein eher beziehungsorientierter Ansatz, der auch Familienmitglieder einbezieht. Dazu bedarf es Verbesserungen in den Beziehungen zwischen Arzt, Patient und Angehörigen. Um ACP im argentinischen Gesundheitssystem zu fördern, sind verschiedene politische Anstrengungen unternommen worden. Für den Abbau von Implementierungsbarrieren bedarf es allerdings besserer Kommunikationsfertigkeiten und einer besseren Koordination zwischen den verschiedenen Anbietern von Gesundheitsleistungen. Ziel der *Shared Care Planning Group Argentina* ist die Förderung von ACP durch entsprechende Forschungs- und Ausbildungsprogramme. In diesem Rahmen wurden inzwischen 236 Gesundheitsfachkräfte in Kurzseminaren, in denen grundlegende Informationen und Fertigkeiten vermittelt werden, für das Thema sensibilisiert und geschult. Für ACP ist in Argentinien allerdings eine

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spezifische Dokumentation erforderlich. Forschungsarbeiten haben verschiedene Implementierungshindernisse offengelegt, zum Beispiel die Unfähigkeit, mit Patientinnen und Patienten zu kommunizieren, und der Mangel an Koordination zwischen einzelnen Gesundheitsteams. Im Rahmen eines neuen Projekts soll die Selbstwirksamkeit von Gesundheitsfachkräften, die Menschen mit amyotropher Lateralsklerose (ALS) hinsichtlich vorausschauender Behandlungsplanung unterstützen, bewertet und ein spezielles Schulungsprogramm evaluiert werden. Die Beteiligung von Patienten und Öffentlichkeit im Hinblick auf ACP ist in Argentinien nach wie vor begrenzt. Als wesentliche Hindernisse haben sich hierbei eine paternalistische Kultur in der Medizin und eine bislang unzureichende Sensibilisierung und Schulung von Gesundheitsfachkräften herausgestellt. Forschungskooperationen mit Spanien und Ecuador haben zum Ziel, Gesundheitsfachkräfte auszubilden und die ACP-Implementierung in anderen lateinamerikanischen Ländern zu evaluieren.

Background of the health care system

Empowering people and communities is one of the components of the new Concept Model of Palliative care from the World Health Organization framework [1]. One of the actionable indicators to asses this component at the national level is the national policy or guideline addressing Advance Care Planning (ACP) of medical decisions for life-sustaining treatment or end-of-life care.

Latin American societies, compared with North American ones, are less individualistic [2,3]. Because self-sufficiency is not the ultimate goal here, radical independence from the social environment is not widely regarded as a desirable end. On the contrary, too much emphasis on self-support, rather than being perceived as empowering, is often seen as weakening people by isolating them from those they depend on. Because of our Mediterranean heritage, Latin Americans care about the qualities they expect from their doctors and others, such as trust, solidarity, and compassion [4].

Life, in these societies, is experienced through interpersonal relationships to elicit attitudes and actions of mutual care, though not conflict. Everyday issues are shared within the private sphere of the family, and illnesses are often seen as matters of great concern for those close to the patient. At the end of life, decision-making responsibilities often involve family members who may take the lead. The fact that Latin America exhibits culturally sensitive social issues suggests that these societies are well-positioned to carry out more relational advanced directives (ADs) focus. Although there is empirical data on this topic, some studies support this hypothesis. In a recent quantitative study on patient perspectives published in Argentina, those who thought these tools were valuable in the healthcare process gave a pivotal role to their families, who were seen as the primary interlocutors by many patients [3].

As a result, while the dominant North American culture has made it challenging to implement a relational approach framed around the concept of ACP that overcomes the problems encountered by the individualistic components of the empowerment movement, most patients in our region may see such an approach as the natural way to approach these decisions. However, another factor that contributes to explaining why patients in Latin America can involve their families in decision-making requires significant improvements in the quality of doctor-patient-family relationships [3].

In the study mentioned earlier, some patients were uncomfortable an writing down their preferences on an ADs form rather than verbally telling their relatives their preferences. Because of families' role frequently, a written document may be perceived as too cold, impersonal, and unnatural. Furthermore, in the presence of trusted carers, notarial requirements and the involvement of witnesses may be viewed as an unnecessary burden. However, one of the main reasons that many patients in this study did not complete an ADs form was fear that physicians or healthcare institutions would misuse these documents, either by actively precipitating the patient's death or by withholding or withdrawing treatments too soon [3].

These fears point to a significant feature of Latin American societies: the rule of Law, which has failed to instil trust in the institutions charged with enforcing their rights [5]. Although completing an ADs form is not required in the ACP process, it can be beneficial in some situations, and patients should feel comfortable issuing them if they wish. Furthermore, a lack of trust in health professionals is incompatible with the type of doctor-patient-family relationship required by ACP. Latin American societies are committed to respecting patients' autonomy, but it is necessary to determine the proper way to use ADs and identify potential facilitators and barriers [3].

Doctors in Latin America should only discuss end-of-life issues with patients if they request it. A decision-making process should respect patients' autonomy while considering their cultural values. In an Argentine study, 86% of participants said they would prefer to participate in decisions about their health, while only 10% would prefer not to be informed if they were seriously ill [6].

Argentina is a federal country divided into 24 provinces. Its healthcare system is heterogeneous. Public health comprises public, social and private institutions. The Ministry of Health oversees all three subsectors of the healthcare system and is responsible for setting regulations and evaluating and collecting statistics. The government maintains a system of public medical facilities universally accessible to everyone in the country. While the public system is highly decentralised and administered at the provincial level, each city will often regulate primary care autonomously.

Still, formal sector workers are also obligated to participate in one of about 300 labour union-run health insurance schemes, which offer differing levels of coverage. Consequently, there are over 300 plans, each branch organised according to the beneficiary's occupation.

Private medical facilities and health insurance also exist in the country. Insurance Plans, an umbrella of organisations for Argentine labour unions, fund and manage the Social Security Sector. The private healthcare sector in Argentina is characterised by significant heterogeneity and comprises many fragmented entities and small networks; it consists of over 200 organisations and covers approximately 2 million Argentines [7].

Policy or legislative efforts/milestones to foster ACP implementation into the national health care system (From AD to ACP)

The first attempts in Argentina to regulate the rights of terminally ill patients date back to 1996 [8,9]. Until then, the withholding or withdrawal of treatment was covered by the 1967 medical practice law. Before 1996, several cases were brought before Argentine courts, mostly involving Jehovah's Witnesses patients whose religious beliefs prohibited them from receiving blood transfusions.

Following extensive media coverage of two relevant cases, a consensus was reached on a bill that guaranteed terminally ill patients, or a family acting on their behalf, the right to refuse medical treatments disproportionate to the prospect of recovery or that prolonged the dying process [8,10].

The Law also governed ADs or living wills, which are legal documents that specify healthcare decisions that must be made if the patient is incapacitated or unable to speak. The right to refuse artificial hydration and nutrition, which the Catholic Church considers basic care, was explicitly listed as one of the practises that could be refused. The Law's full recognition of the patient's autonomy was a distinguishing feature [8].

Argentina is one of the Latin American countries where the issue of ADs has received the most attention and debate [11]. Some court cases have sparked a broad debate about the need to enact legislation to address the issue of ADs.

Establishing Registers of Acts of Self-Defence in some Argentina provinces represents a significant legislative advance in this area. On April 23, 2004, the Buenos Aires Notary Association approved the establishment of the "register of acts of self-protection in anticipation of eventual incapacity," marking the AD's first institutional recognition of bearers of unilateral declarations of will with binding effect for third parties, relatives, doctors, and judges. These registries have since been implemented in Santa Fe, Córdoba, and Chaco provinces. In Argentina, the treatment of Alzheimer's disease varies depending on the institution, the health professionals involved, and the judges, among others, in the absence of specific legislation on the subject and beyond the regulations regarding the request for Informed Consent or the right to therapeutic refusal [12].

The concept that the future of surrogate decision-making, particularly at the end of life, should be based on a broader and more holistic understanding of the decision-making process has matured due to the SUPPORT findings [13,14]. It is commonly known as ACP. It suggested that the entire implementation strategy for ADs be reoriented away from a focus on the formal act of the document itself and towards the development of comprehensive communication processes between professionals, patients, and families to help improve the quality of end-of-life decisions. ADs would be necessary for these processes, but they would not be the only goal but a tool for better decision-making.

ADs guarantee patients the right to decide on their health care. An integrative review of literature conducted between December 2017 and January 2018 explores the use of this instrument. It traces its historical course in Latin American countries with consolidated legislation, such as Puerto Rico. There needed to be more work in disseminating and using this resource.

In Argentina, several laws from different provinces emerged between the late 90s and 2012 (Río Negro, Neuquén, and Córdoba provinces) [15]. In the Province of Córdoba in 2002, Law 10.058 was passed, called "Declaration of Advance Directives for a dignified death", promoting the formation of a Single Registry of Advance Directives. In 2016 this Law was amended, with substantial changes concerning patients being able to refuse hydration and nutrition treatments. Oxygen therapy was no longer mandatory in all cases, as it was no longer considered an "ordinary minimum measure" [16].

Patient autonomy issues at the national level affected the document's acceptance in 2012, necessitating a new debate in Parliament to draft a new law ensuring this right. Legislators enacted Law 26742 due to public pressure [10]. The Argentinian Law established the patient's rights in their relationship with health professionals and institutions. This Law empowers a person of legal age (18 years old) who can draft a directive to consent or refuse preventive or palliative medical treatment. The attending physician must accept them unless they involve euthanasia, which is illegal in Argentina. ADs must be formalised in writing in the presence of two witnesses and recorded by a notary public or a court of first instance, and the patient has the right to revoke them at any time. This Law guarantees a series of rights of patients, including patients with terminal or irreversible illnesses (or family members when they cannot do so), to reject or withdraw therapies or medical procedures when these are disproportionate or when it prolongs the agony. It also expressly states that artificial nutrition and hydration are procedures that, without a curative purpose, are only intended to prolong life and can thus be refused. All laws state that ADs can be revoked at any time, but there is no provision for periodic renewals. This point is crucial because, despite having been made in ADs, new circumstances may arise that the patient did not anticipate, which could have changed his or her mind if he or she had anticipated them. Likewise, the Law regulates ADs as a legal instrument for prospective decision-making [12,17].

In 2016 the National Cancer Institute designed a National Program of Palliative Care (PC) for cancer patients [18]. The procedures of this national programme include the development of networks at various levels of the healthcare system to promote the accessibility of PC, with a primary focus on Primary care; collaborating with interdisciplinary support teams specialised in PC; implementing a training strategy oriented towards the formation of specific teams and the first level of care; and developing mechanisms to ensure a continuous supply and adequate distribution, actions to provide the community with the knowledge and tools needed to support the patient's care process in the family and community environment. Its foundations do not include any strategies to promote ACP.

In this legal context, Argentina has no national ACP program or systematic approach for patients diagnosed with severe or advanced diseases. Therefore, the population or healthcare personnel have yet to discover the concept of ACP.

In 2022, a new law emerged supported by all PC organisations and almost all political forces. Law 27.678 seeks to ensure that patients have access to comprehensive PC services in its different modalities, in the public, private and social security spheres, and to support their families following these provisions [19]. The initiative is founded first and foremost on respect for individuals' lives and well-being, equity in timely access to benefits and respect for patients' dignity and autonomy in decisions about their treatment and care throughout their illness. The Law is set to be implemented in 2023.

Definition and Models of ACP used

Despite more than ten years of the Law of the Rights of the Patients, the recent Law of PC, and a Previous Program of PC for cancer patients, Argentinian society needs more awareness about the meaning of ACP. There are no specific models for this process, and even more: healthcare providers found barriers to implementing ADs in cancer patients [12]. The most significant were a lack of communication skills to deal with this type of conversation with patients, the concealment of information on the disease's diagnosis and prognosis, a lack of coordination between teams that keep track of patients with advanced disease, and resistance from relatives and patients, which limited patients' margins of decision and consent.

In 2017, in Europe, a formal Delphi consensus process developed a definition of ACP and provided recommendations for its application [20]. These recommendations were grouped into five categories: the core elements and aspects of ACP; roles and tasks; timing; legislation and regulation; and evaluation. This consensus inspired us to design training courses for healthcare providers involved in shared decision-making and PC. These courses were updated annually and reached multidisciplinary postgraduate students from a university master's level.

Following Spain, where ACP has been adopted, focusing on relational autonomy and self-efficacy from professionals, the first steps in Argentina also look at the patient's biography and sociocultural context [21–23]. This holistic conception of ACP could strengthen the participation of all healthcare fields in the process. A multidisciplinary approach seems the most appropriate to guarantee a broad, multidimensional, and individualised ACP process [21].

Introduction of the Shared Care Planning Group Argentina

Instead of using the acronym ACP, we chose, when appropriate, the expression shared care planning (SCP) to emphasise the shared nature of the process. For that reason, the Group have chosen this acronym (SCP-Group). It was fitted *ad hoc* in 2021 by healthcare professionals from different disciplines (doctors, psychologists, social workers, advisors) and distributed mainly in Buenos Aires City and other provinces: Córdoba and Santa Fe, under the coordination of Dr Tripodoro and linked with the RED-In-Pal from Pallium Latinoamérica Institute (NGO) [24]. This Group aims to explore the country's current situation of ACP development. We designed research programs and training courses inspired by Spanish experiences and similar cultures.

The Group is actively involved in teaching and research projects. However, it has yet to be recognised as a formal group. It promotes the spread of ACP nationally and to other Latin American countries.

Groups of patients addressed

The type of patient who refuses treatment and the therapies that can be withheld or withdrawn have changed due to new legislation [8]. Although there has recently been widespread agreement on the importance of including individuals who are not legally competent in legislation, including minors and the incompetent was initially opposed. In both cases, the interventions and treatments that could be withheld or withdrawn varied depending on what was considered euthanasia. In the early debates in Argentina, the interruption of life-sustaining treatments was considered euthanistic; however, the 2012 law explicitly provided for withholding and/or withdrawing these treatments without eliciting significant opposition. However, euthanasia was seen as the moral limit of the practises accepted in legislation in both debates, even though the concept of what was considered euthanasia has partially changed, indicating that the limits of what is morally acceptable or tolerable may shift. Nowadays, at least three projects of euthanasia laws are waiting for legislative discussions. The public's conception of the issue and, consequently, the scope and outcome of the discussions were influenced by the political setting and the diverse ways that "death with dignity" entered the legislative agenda each time [25].

In medical end-of-life care, personal dignity and individual freedom are at stake. The shifts in the debates show how personal autonomy and patients' interests have taken centre stage in medical settings. The social and political contexts in which end-of-life care was introduced shaped the frameworks in which it was constructed as a problem. The sociology of public problems has shown that how an issue is defined influences how people respond. How "death with dignity" entered the public domain in Argentina shaped the very definitions of the term. "Dying with dignity" meant different things to different people. "Death with Dignity" must be viewed as a living concept, a stage in which moral, scientific, religious, and political discourses construct socially acceptable modes of death [8].

Education/Training of Health care professionals and non-healthcare professionals in ACP

In Argentina, there still needs to be more studies that provide evidence on ACP focused on the experiences and skills of healthcare professionals to promote reflection and put it into practice. Aligned with the WHO Concept PC model, the SCP-Group tried sensitising primary care and PC professionals to ACP awareness [1]. One indicator proposed to assess PC development in the country is the "Existence of national policy or guideline addressing ACP of medical decisions for the use of life-sustaining treatment or end-of-life care".

SCP-Group Argentina recently studied the perceived self-efficacy of healthcare professionals to start ACP processes with patients with advanced chronic diseases [26]. One of the goals of this initiative was to spark discussion before the specific training course and to aid in the development of appropriate teaching methods based on professional perceived self-efficacy. The Group agreed that people affected by severe or life-threatening illnesses should have, at an early stage, the opportunity to receive transparent information about life-sustaining treatment and palliative care; and express in advance their values and preferences about life-sustaining treatment and the care they will receive. The ACP process should also engage family members [20].

Following these recommendations, the SCP-Group Argentina sensitised and trained 236 healthcare providers in short courses to introduce basic information and skills based on their previous self-efficacy perceptions [26,27]. Healthcare professionals must be able to respond to the opinions and concerns of the patient's family during the decision-making process, such as by informing family members of the decision's repercussions and helping them prepare for end-of-life care. The findings should encourage more tailor-made future pieces of training programs. The future evaluation of self-efficacy and training outcomes should be included [26]. These findings help multi-level discussion about ACP, which means not only at a professional level but at the national and community level.

Information Materials used, Documentation and Digitalization of ACP processes in the Healthcare sector and beyond

There needs to be specific documentation for ACP in Argentina. Apart from the ADs' specific legal document, all medical decisions and patientś preferences must be written on the medical records. Usually, doctors ask patients and/or relatives to sign their agreement, mainly if it compromises withdrawing or withholding treatments.

Research agenda on ACP

In 2018, a study supported by the National Cancer Institute examined how oncologists and PC specialists in Argentina view advanced end-of-life care planning for cancer patients [12]. This qualitative research investigated the obstacles to patient decision-making in end-of-life care based on semi-structured interviews with experts from several fields. Even though ACP and instruments like ADs were accepted, obstacles to their implementation were found. The main issues were the inability to have these conversations with patients, the failure to disclose the disease's diagnosis and prognosis, the lack of coordination between the teams responsible for monitoring patients with severe disease and the opposition of patients' loved ones, which reduces patients' freedom of choice and consent [12].

In December 2022, the SCP-Group Argentina, funded by the Ministry of Science, Technology and Innovation, launched the project "Assessment of self-efficacy perceived by health professionals on Shared Care Planning in Patients with Amyotrophic Lateral Sclerosis (ALS): design, multicentre implementation and Evaluation of a training program". It aims to characterise the perceived self-efficacy in ACP by health professionals who assist people with ALS in Argentina before and after a specific multicentre training program. It will be developed in six months during the current year. The Esteban Bullrich Foundation also support this initiative.

Patient and public involvement (patient movement) in research and development of ACP

To our knowledge, there is no group, association or movement of patients or citizens in advocacy of ACP in Argentina. Including people from patient associations gathered for different diseases (ALS, COPD, Alzheimer's) could be an excellent place to trigger awareness about decision-making and the right to decide about medical treatments and the place of care.

Main Challenges and Barriers

ACP is still hidden by paternalism. Physicians in Latin America were still primarily practising medicine according to the traditional paternalistic model, which places more emphasis on the patient's right to self-determination than on the duties arising from beneficence [3].

A study published in Argentina in 2012 found that older doctors treating patients with Alzheimer's disease were hesitant to talk to patients who could still make decisions [28]. They claimed that there was an implicit understanding, supported by patients, that family members should make decisions with the help of doctors. Difficulties in ADs implementation, predicting the evolution of a patient's disease, the period between the discussion and ADs implementation, and lack of legislation and specific institutional policies were other factors that conditioned the discussion.

In a cancer patients study in 2017, participants positively valued the possibility of planning end-of-life care according to the preferences of their cancer patients. Still, they mentioned different situations, mainly focused on communication skills and lack of coordination, that hinder the implementation of these practices [12].

These barriers were similar to the Spanish contexts in coincidence with our Mediterranean roots [3,4]. In Spain, there are four primary reasons. ADs have little effect on clinical practice:

1. Lacking training of healthcare professionals about the end of life and AD
2. Absence of a public campaign to raise awareness of AD
3. Bureaucracy to document and implement ADs
4. In Spain, traces of a paternalistic medical culture still exist [29].

It is important to note that although ADs have garnered significant attention in the legal communities, health professionals have yet to share this emphasis [15]. It might be because professionals do not fully understand this tool's capabilities, both in promoting patient autonomy and as a safety net for them against potential problems concerning their interactions with the patient's family in circumstances of a terminal illness. It makes sense to assume that the difficulty of dealing with patients close to passing away correlates to the difficulty of resolving the AD issue. So, creating such a document could open the lines of communication, allowing worries, uncertainties, and anxieties to be expressed and explained, strengthening bonds and raising the quality of life [15].

Collaborations with other countries regarding ACP

Last year, the SPC-Group Argentina joined the AEPCA (Asociación Española de Planificación Compartida de la Atención) in collaborations, training and research opportunities. This initiative proposed a new research collaborative project between Ecuador and Argentina with the scope of Latin American countries. We aim first to train healthcare professionals using the self-efficacy scale on ACP, then by evaluating the results of both training and ACP implementations in practice. The research group invited the Latin American Association on Palliative Care (ALCP) to support the project inviting all country members to be engaged. The RED-In-Pal from Pallium Latinoamérica Institute (Argentina), The University of Loja (Ecuador) and the AEPCA (Spain) encouraged other countries to follow the process of training and awareness and put it into clinical practice.

Conflict of interest

All authors declare there they have no conflict of interest.

CRediT author statement

All authors VT, SDG, JF, VIV, CQ, CV, and LF contributed with the manuscript and revised the final version.

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