Junta de Andalucía
Consejería de Salud y Familias

RED PAL

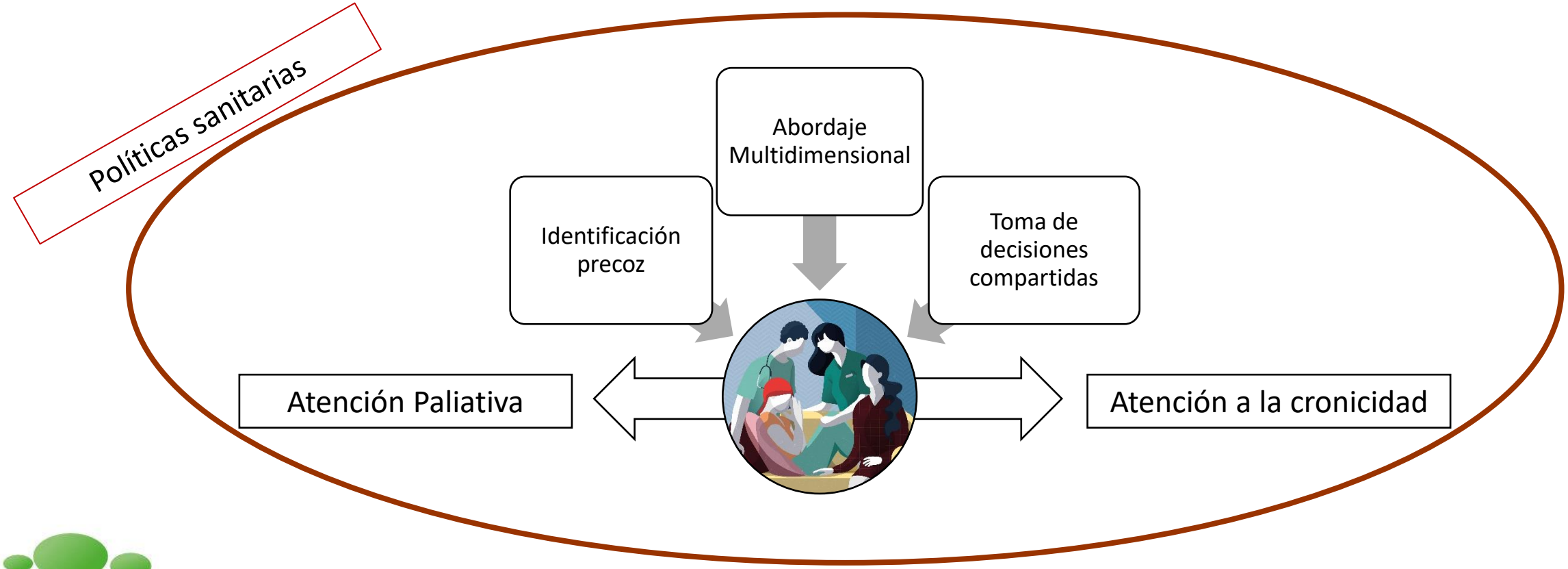
RED DE CUIDADOS PALIATIVOS DE ANDALUCÍA

Planificación compartida de la atención: evolución de los últimos 10 años
12 de mayo, Día Internacional de la enfermería

Cristina Lasmarías
Enfermera. Doctora en Ciencias de la Salud y Sociales
Instituto Catalán de Oncología

Qué desarrollo tiene la PCA en nuestro contexto

Las bases

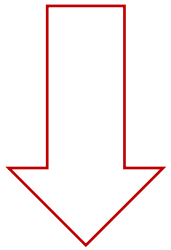


Santaeugènia SJ, Contel JC, Vela E, Cleries M, Amil P, Melendo-Azuela EM, et al. Characteristics and Service Utilization by Complex Chronic and Advanced Chronic Patients in Catalonia: A Retrospective Seven-Year Cohort -Based Study of an Implemented Chronic Care Program. Int J Environ Res Public Health. 2021;18(18):9473.

La autonomía clave en la transformación

Autonomía individualista
Corriente anglosajona

Autonomía relacional
Corriente europeísta



Decisiones libres, con conocimiento, basadas en los propios valores

- The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report.Research. 1979.
- Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 7th ed. Oxford University Press, editor. New York; 2013.
- Institut Borja de Bioètica. El concepte d'autonomia en la medicina occidental. Bioètica & debat. 2011;17(62).

Autonomía relacional

La autonomía relacional es aquella en la que se entiende al **sujeto autónomo** no como un ser individual, racional y libre de presiones externas sino, **principalmente**, como alguien **que vive y se comprende dentro** de una **cultura**, un **entorno**, una **biografía**, una **sociedad** o una **religión**

Autonomía relacional y planificación de decisiones anticipadas

1) reconoce la **importancia** de las **relaciones sociales** y **familiares**, por ello, **la biografía** de la persona;

2) es un proceso dinámico, refleja la **naturaleza oscilante** de la **autonomía**, especialmente en la situación de la **enfermedad crónica**;

3) reconoce la **vulnerabilidad** de la persona inherente al **sufrimiento** que genera la enfermedad;

- Killackey T, Peter E, Maciver J, Mohammed S. Advance care planning with chronically ill patients: A relational autonomy approach. Nurs Ethics. 2020;27(2):360-71.
- Gómez-Vírseda C, De Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: A contextualized approach to real-life complexities. BMC Med Ethics. 2020;21(1):1-14.
- Miller BL. Autonomy and the Refusal of Lifesaving Treatment. Hastings Cent Rep. 1981;11(4):22.

Desarrollo de la Planificación de Decisiones Anticipadas

- **Desarrollo internacional**
  - Estudio SUPPORT, 1995
  - Delphi Sudore, 2017
  - Delphi Rietjens, 2017


Original Contributions

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)


Review

Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

- **Desarrollo nacional**
  - Guía andaluza de Planificación Anticipada de las Decisiones, 2013
  - Model Català de Planificació de decisions anticipades, 2014
  - Guía PDA-SM, 2015
  - Asociación Española de Planificación Compartida de la Atención, 2017

AEPCA
Asociación Española de Planificación Compartida de la Atención

- The SUPPORT Principal Investigators. A Controlled Trial to Improve Care for Seriously III Hospitalized Patients. JAMA. 1995;274(20):1591.
- Rietjens JAC, et al. European Association for Palliative Care (EAPC). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. The Lancet Oncology. 2017; 18(9): e543-e551.
- Sudore RL, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017;18(9):e543-.e551.

Proyectos en España...

Programa de Decisiones Anticipadas 2015.
Ministerio de Salud PV. I Saralegui

Modelo Catalán de PDA. 2014.
Càtedra de CP/ Departament de Salut

Regulación de la Planificación Compartida de la Atención, 2022

Development and implementation of an advance care planning program in Catalonia, Spain

Cristina Lasmarias, B.A., R.N., M.SC.[1,2,3], Amor Aradilla-Herrero, R.N., PH.D.[4], Sebastià Santaeugènia, M.D., PH.D.[3,5], Carles Blay, M.D., PH.D.[3,6], Sara Delgado, M.D.[7], Sara Ela, B.A.[1,2], Núria Terribas, B.L.[8] and Xavier Gómez-Batiste, M.D., PH.D.[1,2,3]

[1]The Qualy Observatory-World Health Organization Collaborating Center for Public Health Palliative Care Programs (WHOCC-ICO), Catalan Institute of Oncology, L'Hospitalet de Llobregat, Barcelona, Spain; [2]Chair of Palliative Care, University of Vic-Central University of Catalonia, Vic, Barcelona, Spain; [3]Catalonia Chronic Care Research Group, University of Vic-Central University of Catalonia, Vic, Barcelona, Spain; [4]Escuela Universitaria de Enfermería Gimbernat, Autonomous University of Barcelona, Sant Cugat del Vallès, Barcelona, Spain; [5]National Strategy of Integrated and Chronic Care, Ministry of Health, Government of Catalonia, Barcelona, Spain; [6]Medicine, University of Vic - Central University of Catalonia, Vic, Barcelona, Spain; [7]St Luke's Hospice, London, United Kingdom and [8]Chair of Bioethics, University of Vic-Central University of Catalonia, Fundació Grifols, Barcelona, Spain

Abstract

Objective. Implementation of an advance care planning (ACP) program for people with advanced chronic conditions is a complex process. The aims of this paper are to describe (1) the development of the ACP program in Catalonia, Spain, for patients with advanced chronic conditions and complex needs and (2) the preliminary results of the implementation of this program in health and social services.

Method. The ACP program was developed and implemented in a four-stage process as follows: (1) design and organization of the project; (2) selection of the professionals to carry out the project; (3) creation of four working groups to develop the conceptual model, guidelines, training program, and perform a qualitative evaluation; and (4) project implementation.

Result. The following deliverables were completed: (1) conceptual framework document; (2) practical guidelines for the application of the ACP; (3) online training course (3,763 healthcare professionals completed the online course, with an overall satisfaction rating of 8.4 on a 10-point scale); and (4) additional training activities (conferences, short courses, and seminars) in between 2015 and 2017.

Significance of results. This project was led by the Catalan Ministry of Health. The strengths of the project development include the contribution of a wide range of professionals from the entire region, approval by the Catalan Bioethics Committee and the Social Services Ethics Committee, and the ongoing validation by members of the community. A standardized online training course was offered to all primary care professionals and included as a quality indicator for continuing education for those professionals in the period 2016–2020. The main outcome of this project is the establishment of a pragmatic ACP throughout the region and training of the health and social care professionals involved in the care of advanced chronic patients.

Planificación Anticipada de las Decisiones. 2013.
Consejería de Salud

Kayros Project 2014. J Judez

Planificación compartida de la atención (PCA)

"La **planificación compartida de la atención** es un **proceso deliberativo, relacional y estructurado**, que facilita la **reflexión** y **comprensión** de la vivencia de enfermedad y el cuidado entre las personas implicadas, centrado en la persona que afronta una trayectoria de enfermedad, para identificar y expresar sus preferencias y expectativas de atención.

Su objetivo es **promover la toma de decisiones compartida** en relación al contexto actual y los retos futuros de atención, como aquellos momentos en que la persona no sea competente para decidir."

https://www. aepca.es/

Peter Saul: ***"To be respected, to be informed, to be involved"***

Original Article

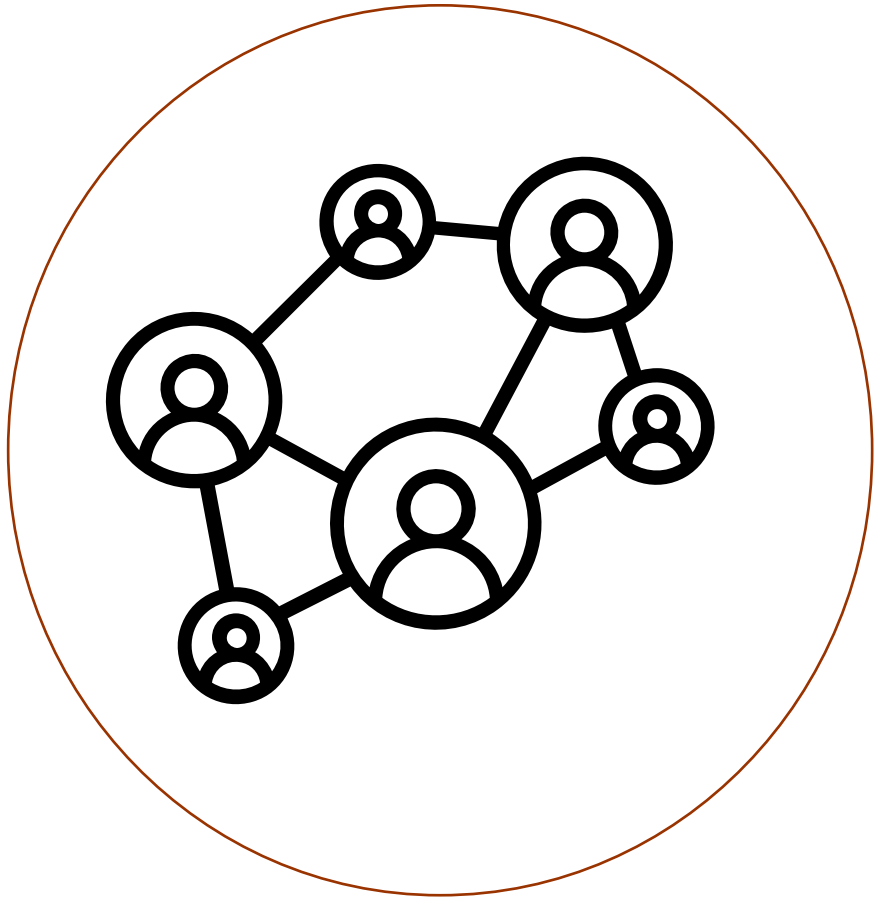
Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

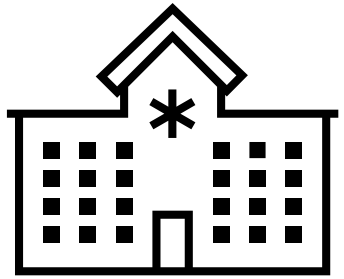
Results. Panelists identified several tensions concerning ACP concepts such as whether the definition should focus on conversations vs. written advance directives; patients' values vs. treatment preferences; current shared decision making vs. future medical decisions; and who should be included in the process. The panel achieved a final consensus one-sentence definition and accompanying goals statement: "Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness." The panel also described strategies to best support adults in ACP.

Conclusions. A multidisciplinary Delphi panel developed a consensus definition for ACP for adults that can be used to inform implementation and measurement of ACP clinical, research, and policy initiatives. J Pain Symptom Manage 2017;■ :■—■. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

- **Entender (*darse cuenta*) y compartir** preferencias, valores, expectativas, deseos en relación tratamientos futuros
- **Ayudar a garantizar** que la persona recibe la asistencia de acuerdo con estos valores, objetivos y preferencias durante la enfermedad crónica avanzada
- **Escoger el representante** para los momentos en los que la persona no pueda decidir

La participación de las personas implicadas





Pearlman RA, Cole WG, Patrick DL, Starks HE, Cain KC. Advance care planning: eliciting patient preferences for life-sustaining treatment. Patient Educ Couns. 1995;26(1-3):353-61..

Implicación de las personas enfermas

***Readiness* (predisposición) y *Engagement* (Compromiso)**

Fried et al.

Estadios de cambio (Modelo transteórico)

Precontemplación
Contemplación
Preparación
Acción
Mantenimiento
Finalización

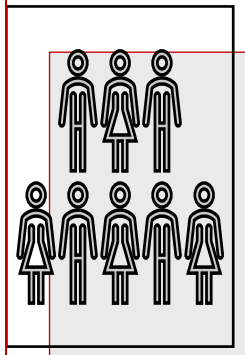
Sudore et al.

Factores para el cambio (Teoría social cognitiva)

Conocimiento
Contemplación
Autoeficacia
Predisposición

- Prochaska JO, Redding CA, Evers KE. The transtheoretical model and stages of change. En: Glanz K, Rimer BK, Viswanath K, editores. Health Behavior and Health Education Theory, Research, and Practice. 4.a ed. San Francisco: John Wiley & Sons, Ltd; 2008. p. 97-121.
- Fried TR, Redding CA, Robbins ML, Paiva A, O'Leary JR, Iannone L. Stages of Change for the Component Behaviors of Advance Care Planning. J Am Geriatr Soc. 2010;58(12):2329-36.
- Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191-215.

Implicación de los profesionales: dificultades



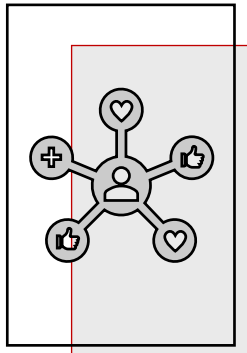
PERSONAS ENFERMAS

-"no están preparadas"

-Incertidumbre pronóstica

-Deterioro cognitivo-competencia

-Protección de la familia

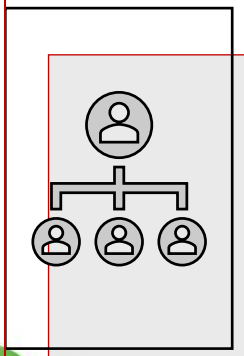


ASPECTOS SOCIO-CULTURALES

-Modelo social predominante

-Condicionantes económicos

-Aspectos culturales o religiosos



ORGANIZACIÓN

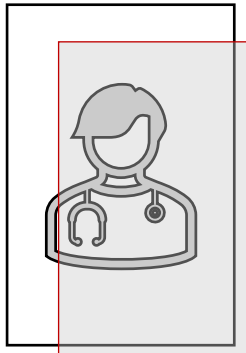
-Falta de tiempo

-Carga asistencial

-Falta de continuidad en la atención

-Baja calidad de los registros

-Incentivación económica



PROFESIONALES

-Poca sensibilidad hacia el tema ("esto no me compete")

-Baja autoeficacia

-Falta de formación

-Falta de competencias clínicas y éticas

- Risk J, Mohammadi L, Rhee J, Walters L, Ward PR. Barriers, enablers and initiatives for uptake of advance care planning in general practice: A systematic review and critical interpretive synthesis. BMJ Open. 2019;9(9):1-17.Street RL, Millay B. Analyzing Patient Participation in Medical Encounters. Health Commun. 2001;13(1):61-73..
- Lund S, Richardson A, May C. Barriers to advance care planning at the end of life: an explanatory systematic review of implementation studies. PLoS One. 2015;10(2):e0116629.
- Limón E, Lasmarías C, Blay C. Planificación de decisiones anticipadas: Factibilidad y barreras para su implementación. FMC - Form Médica Contin en Atención Primaria. 2018;25(5):259-61.
- Glaudemans JJ, De Jong AE, Philipsen BDO, Wind J, Willems DiL. How do Dutch primary care providers overcome barriers to advance care planning with older people? A qualitative study. Fam Pract. 2018;36(2):219-24.
- Granero-Moya N, Frías-Osuna A, Barrio-Cantalejo IM, Ramos-Morcillo AJ. Dificultades de las enfermeras de atención primaria en los procesos de planificación anticipada de las decisiones: un estudio cualitativo. Aten primaria. 2016;48(10):649-56.

Autoeficacia

"*la creencia en las propias capacidades para organizar y ejecutar los cursos de acción requeridos para manejar situaciones futuras*"

La creencia de eficacia influye sobre el modo de **pensar, sentir, motivarse y actuar** de las personas

- Expectativas de eficacia (*me siento capaz de iniciar un proceso de PDA con un/a paciente*)
- Expectativas de resultados (*hacer un proceso de PDA mejora el conocimiento que tengo de los deseos y expectativas del/la paciente)*

- Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191-215.
- Bandura A. Ejercicio de la eficacia personal y colectiva en sociedades cambiantes. En: Bandura A, editor. Autoeficacia: cómo afrontamos los cambios de la sociedad actual. Bilbao: Desclée De Brouwer; 1999. p. 19-54.

Delphi Rietjens 2017: indicadores PCA

Recomendaciones sobre la evaluación	Porcentaje*	Acuerdo		Rango Intercuartil‡	Comentarios escritos por el panel de expertos en las rondas 2 y 3 (n)
		Porcentaje*	Mediana†		
27. Dependiendo de los objetivos del estudio o proyecto, se recomienda valorar los siguientes conceptos:					
a) Conocimiento de PDA (evaluado por las personas, familia y profesionales sanitarios)	91	1	1	..	
b) Autoeficacia para iniciar una PDA (evaluado por las personas, familia y profesionales sanitarios)	84	2	1	..	
c) Predisposición a iniciar una PDA (evaluado por las personas, familia y profesionales sanitarios)	92	1	1	..	
d) Identificación de objetivos y preferencias	96	1	0	..	
e) Comunicación sobre objetivos y preferencias con la familia	96	1	1	..	
f) Comunicación sobre objetivos y preferencias con profesionales sanitarios	98	1	1	..	
g) Identificación del representante personal	92	1	1	..	
h) Registro de objetivos y preferencias	95	1	0	..	
i) Revisión de las discusiones y documentos a lo largo del tiempo	96				
j) Hasta qué grado se consideró que la PDA tenía sentido y resultaba útil (evaluado por las personas, familia, y profesionales sanitarios)	96				
k) Calidad de las conversaciones (evaluado por las personas, familia, facilitadores y profesionales sanitarios, o ambos)	90				
l) Satisfacción con el proceso de PDA (evaluado por las personas, familia y profesionales sanitarios)	94				
m) Sentido de la atención sanitaria	83				
n) Si la atención recibida fue consistente con los objetivos y preferencias expresados por la persona	92	1	0	..	
28. Se recomienda identificar y desarrollar medidas de resultados basadas en estos conceptos para que puedan ser agrupados y comparados en estudios o proyectos; tales medidas deberían tener propiedades psicométricas sólidas, ser suficientemente breves, y validadas en grupos de población significativos[78]	89	1	1		37

Med Paliat. 2019;26(3):236-249

SECPAL

Medicina Paliativa

www.medicinapaliativa.es

ARTÍCULO ESPECIAL

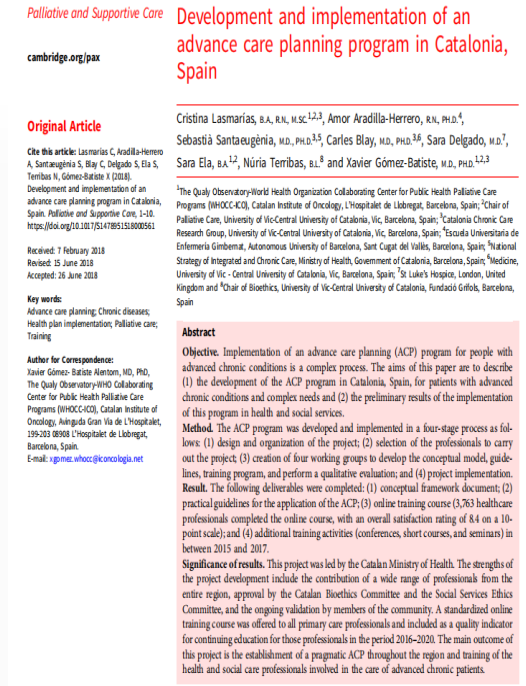
Definición y recomendaciones para la planificación de decisiones anticipadas: un consenso internacional apoyado por la *European Association for Palliative Care* (EAPC)

Cristina Lasmarías Martínez[*1-3], Sara Delgado Girón[4], Judit A. C. Rietjens[5], Ida J. Korfage[5] y Xavier Gómez-Batiste[1,2]

Esto suscita algunas preguntas…..

www.menti.com and use the code **4144 8217**

https://www.menti.com/v6wu8ventr



Palliative and Supportive Care

cambridge.org/pax

Original Article

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Key words:
Advance care planning; Chronic diseases; Health plan implementation; Palliative care; Training

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Abstract

Objective. Implementation of an advance care planning (ACP) program for people with advanced chronic conditions is a complex process. The aims of this paper are to describe (1) the development of the ACP program in Catalonia, Spain, for patients with advanced chronic conditions and complex needs and (2) the preliminary results of the implementation of this program in health and social services.

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Significance of results. This project was led by the Catalan Ministry of Health. The strengths of the project development include the contribution of a wide range of professionals from the entire region, approval by the Catalan Bioethics Committee and the Social Services Ethics Committee, and the ongoing validation by members of the community. A standardized online training course was offered to all primary care professionals and included as a quality indicator for continuing education for those professionals in the period 2016–2020. The main outcome of this project is the establishment of a pragmatic ACP throughout the region and training of the health and social care professionals involved in the care of advanced chronic patients.

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Original Article

Spanish Cross-Cultural Adaptation and Psychometric Properties of the Advance Care Planning Self-Efficacy: A Cross-Sectional Study

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Abstract

Background: Perceived self-efficacy in advance care planning (ACP) is frequently used to measure the impact of ACP programs for professionals responsible for advanced chronic patients. A validated ACP Self-Efficacy (ACP-SE) scale is not currently available in Spanish.
Objective: To culturally adapt and validate Baughman's ACP-SE scale into Spanish (ACP-SEs).
Methodology/Design: An instrumental study was performed in two phases: (1) cultural adaptation of the ACP-SE scale and (2) psychometric properties measurement.
Setting/Participants: The survey was sent to 5785 professionals: physicians, nurses, psychologists, and social workers, members of scientific associations in the areas of primary care, geriatrics, and palliative care in Catalonia, Spain.
Results: Five hundred thirty-eight questionnaires were obtained, respondents were physicians (69.0%) and nurses (28.4%) and mean age was 47 years (standard deviation [SD] = 10.1). Most were women (79.6%), 68% had >15 years of professional experience, and 80.7% worked in primary care. Internal consistency was high (Cronbach's alpha = 0.95) and showed a unidimensional structure explaining 56.2% of total variance. Mean score was 67.37 (SD = 16.1). Variables associated with greater self-efficacy were previous training ($t = -3.23$, $df = 273.76$, $p = 0.001$), previous participation in ACP processes ($t = -6.23$, $df = 521$, $p < 0.001$), and membership in geriatric or palliative care scientific association ($p < 0.001$). ACP-SEs positively correlated to other compared scales.
Conclusion: The ACP-SE scale demonstrates adequate psychometric properties. This is the first self-efficacy scale for ACP in Spanish. It should facilitate a better understanding of implementation processes related to ACP programs for professionals involved in caring for patients with advanced diseases.

Keywords: advance care planning; psychometrics; reproducibility of results; self-efficacy

International Journal of Environmental Research and Public Health
MDPI

Article

Primary Care Professionals' Self-Efficacy Surrounding Advance Care Planning and Its Link to Sociodemographics, Background and Perceptions: A Cross-Sectional Study

Cristina Lasmarías [1,2], Amor Aradilla-Herrero [3,*], Cristina Esquinas [4,5], Sebastià Santaeugènia [3,6], Francisco Cegri [7,8], Esther Limón [9,10] and Mireia Subirana-Casacuberta [11,12]

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Abstract: Primary care (PC) professionals have been considered the most appropriate practitioners for leading Advance care planning (ACP) processes with advanced chronic patients. Aim: To explore how PC doctors' and nurses' self-efficacy surrounding ACP is linked to their sociodemographic characteristics, background and perceptions of ACP practices. Methods: A cross-sectional study was performed. Sociodemographics, background and perceptions about ACP in practice were collected using an online survey. The Advance Care Planning Self-Efficacy Spanish (ACP-SEs) scale was used for the self-efficacy measurement. Statistical analysis: Bivariate, multivariate and backward stepwise logistic regression analyses were performed to identify variables independently related to a higher score on the ACP-SEs. Results: N = 465 participants, 70.04% doctors, 81.47% female. The participants had a mean age of 46.45 years and 66.16% had spent >15 years in their current practice. The logistic regression model showed that scoring ≤ 75 on the ACP-SEs was related to a higher score on feeling sufficiently trained, having participated in ACP processes, perceiving that ACP facilitates knowledge of preferences and values, and perceiving that ACP improves patients' quality of life. Conclusions: Professionals with previous background and those who have a positive perception of ACP are more likely to feel able to carry out ACP processes with patients.

Keywords: advance care planning; primary care; self-efficacy

Publicaciones

Publicación 1

Lasmarías C, Aradilla-Herrero A, Santaeugènia S, Blay C, Delgado S, Ela S, et al. Development and implementation of an advance care planning program in Catalonia, Spain. Palliat Support Care. 2019;17(4):415-24. DOI: 10.1017/S1478951518000561. *Impact factor; 1.968 (2019) ; Quartil: Q2*

Publicación 2

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Publicación 3

Lasmarías C.; Aradilla-Herrero A.; Esquinas C.; Santaeugènia S.; Cegri F.; Limón E.; Subirana-Casacuberta M. Primary Care Professionals' Self-Efficacy Surrounding Advance Care Planning and Its link to Sociodemographics, Background and Perceptions: A Cross-Sectional Study. Int. J. Environ. Res. Public Health. 2021;18(17): 9034. DOI: 10.3390/ijerph18179034. *Impact factor; 3.390; Quartil: Q1*

Palliative and Supportive Care

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Development and implementation of an advance care planning program in Catalonia, Spain

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Key words:
Advance care planning; Chronic diseases; Health plan implementation; Palliative care; Training

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Abstract

Objective. Implementation of an advance care planning (ACP) program for people with advanced chronic conditions is a complex process. The aims of this paper are to describe (1) the development of the ACP program in Catalonia, Spain, for patients with advanced chronic conditions and complex needs and (2) the preliminary results of the implementation of this program in health and social services.

Method. The ACP program was developed and implemented in a four-stage process as follows: (1) design and organization of the project; (2) selection of the professionals to carry out the project; (3) creation of four working groups to develop the conceptual model, guidelines, training program, and perform a qualitative evaluation; and (4) project implementation.

Result. The following deliverables were completed: (1) conceptual framework document; (2) practical guidelines for the application of the ACP; (3) online training course (3,763 healthcare professionals completed the online course, with an overall satisfaction rating of 8.4 on a 10-point scale); and (4) additional training activities (conferences, short courses, and seminars) in between 2015 and 2017.

Significance of results. This project was led by the Catalan Ministry of Health. The strengths of the project development include the contribution of a wide range of professionals from the entire region, approval by the Catalan Bioethics Committee and the Social Services Ethics Committee, and the ongoing validation by members of the community. A standardized online training course was offered to all primary care professionals and included as a quality indicator for continuing education for those professionals in the period 2016–2020. The main outcome of this project is the establishment of a pragmatic ACP throughout the region and training of the health and social care professionals involved in the care of advanced chronic patients.

Publicación 1

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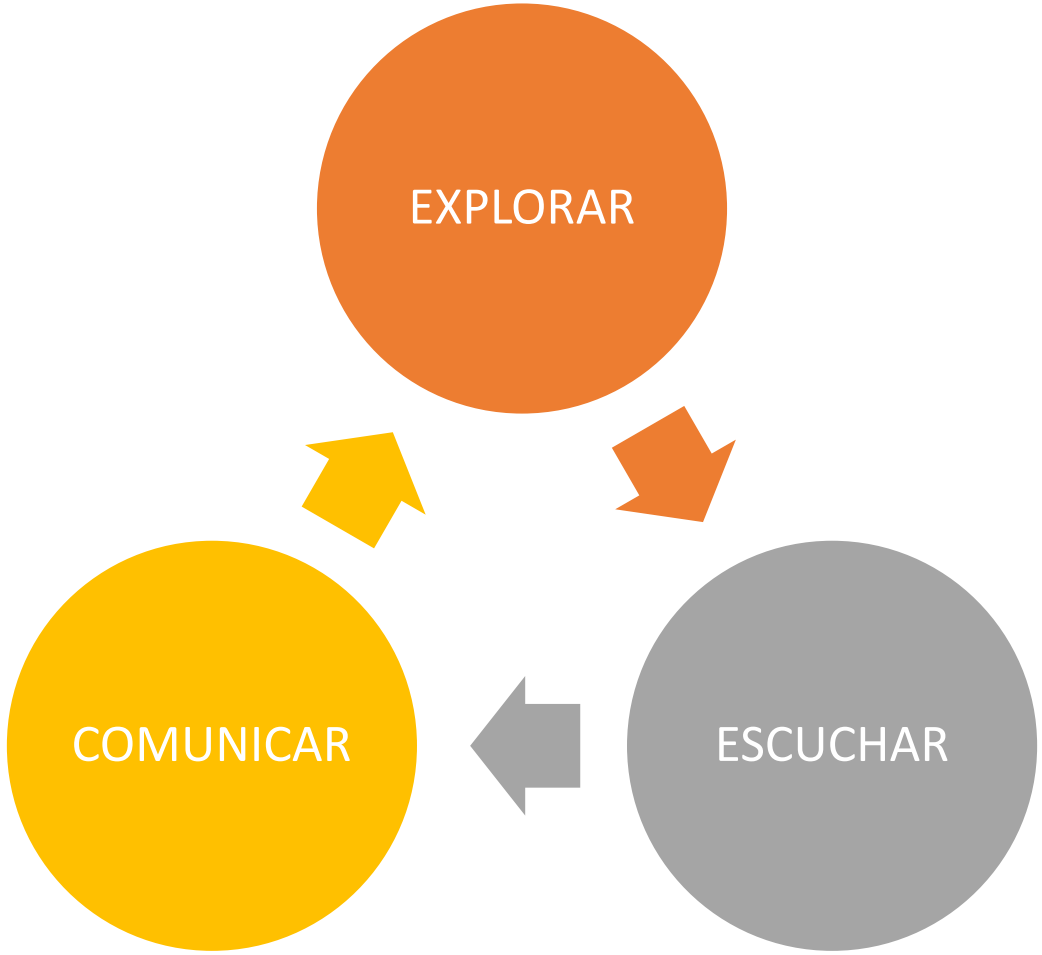
Resultados

1. Descripción de las bases para el desarrollo de un programa de PDA
2. Justificación de su integración en las políticas sanitarias públicas de atención a la cronicidad a partir de una experiencia concreta
3. Definición de un marco teórico propio que incorporó una aproximación realista a la práctica asistencial
4. Descripción de los productos generados: materiales de soporte para el desarrollo de la PDA y formación
5. Identificación de algunos indicadores de impacto: diseminación del concepto, y satisfacción y cobertura de la formación

2015 - 2017

- N=3763: 94% médic@s/ enfermer@s
- 66% de atención primaria
- 8.4/10 satisfacción con la formación
- Evaluación cualitativa: “todos los profesionales deberían realizar este curso. Ofrece una mirada global de lo que es la PDA, y nos ayuda a ser conscientes de su importancia, motivando para su puesta en práctica”

Cómo se lleva a cabo



PLANIFICACIÓ DE DECISIONS ANTICIPADES (PDA)

Grup investigador:

Cristina Lasmarías, Xavier Gómez-Batiste, Jordi Amblàs, Xavi Costa, Sara Delgado, Sarah Mir, Anna Formiguera, Amor Aradilla

1. Preparació

- Identificar la persona que se'n pot beneficiar, valorar-ne la competència.
- Planificar quin és el moment més adequat.
- Reflexionar els aspectes més rellevants que s'haurien d'abordar.
- Definir un cronograma i un pla, un guió bàsic.
- Identificar les altres persones i professionals que s'haurien d'implicar.

2. Proposta

- Explicar què és la PDA i aclarir dubtes.
- Respectar una no acceptació a participar en la PDA i registrar la proposta a la història clínica.
- Entregar un document informatiu i donar temps definit per reflexionar-hi.
- Acordar una data per a la primera trobada.
- Consensuar els detalls de la trobada: acompanyants, revisió de DVA previ, espai, durada...

3. Diàleg

- Escollir bé l'espai.
- Implicar les persones necessàries: altres professionals, representant, tutor legal...
- Entrevista semi-estructurada.
- Explorar a través de les diferents trobades i les àrees següents:

ÀREES D'EXPLORACIÓ

1. Coneixement i percepció

- Descripció dels problemes de salut
- Creences relatives a la causa de la malaltia
- Creences relatives al pronòstic
- Creences sobre les conseqüències
- Creences sobre el marge actuació terapèutica

2. Valors i vivència

- Aspectes de la malaltia més importants
- Aspectes de l'atenció més importants
- Preocupacions, pors, neguits
- Valors vers la salut i la malaltia
- Antecedents de dols i la vivència dels mateixos
- Antecedents d'afrontament
- Expectatives

3. Decisions concretes

- Situacions concretes previsibles
- Condicions d'adequació de l'esforç terapèutic
- Lloc d'atenció prioritari en els moments de crisi o descompensacions
- Sol·licituds especials
- Designació de representant
- Aspectes relacionats amb el comiat, funeral...

4. Validació

- Contrastar amb la persona, després de cada trobada, que s'han entès bé els aspectes importants.
- Revisar conjuntament el registre que se'n fa a la història clínica.

5. Registre

- Registrar cada trobada a la història clínica: desenvolupament, informació rellevant, acords als que s'ha arribat...
- Fer arribar un resum final als implicats i als professionals responsables d'enregistrar-lo al PIIC.
- Garantir el registre del resum final al PIIC.
- Entregar una còpia al pacient, a la residència, etc. si així ho autoritza la persona.
- Estil de redacció (proposta): les 3 C, Claredat, concisió, comprensibilitat.

6. Re-avaluació

- Si la persona ho demana.
- Si hi ha un canvi clínic evolutiu que ho aconselli (noves malalties, noves complicacions, nous tractaments...)
- Si els professionals ho consideren oportú.
- Si hi ha canvis importants en la situació de la persona (canvis de representant, etc.)
- Si hi ha canvi de professional responsable.

Quines preguntes ens poden ajudar: Quines coses són més importants per a vostè en aquesta situacio? • Què hauríem de saber de vostè en relació als seus valors, conviccions, expectatives, preferències, pors o preocupacions que caldria fer constar en la HC? • On li agradaria que el cuidessin quan s'apropi el final? • Quines serien les seves prioritats en el cas que les coses anessin malament? • Si les coses no anessin del tot bé, vostè prioritzaria la qualitat de vida o la quantitat de temps viscut? • Fins a on sap la seva família en relació a les seves preferències, desitjos, preocupacions?

DIÁLOGO

- Escoger bien el espacio
- Implicar a las personas necesarias: otros profesionales, representante, tutor legal…
- Entrevista semi-estructurada
- Explorar a través de distintos encuentros las **SIGUIENTES ÁREAS**:

CONOCIMIENTO Y PERCEPCIÓN

- Descripción de los problemas de salud
- Creencias relativas a las causas de la enfermedad
- Creencias relativas al pronóstico
- Creencias relativas a las consecuencias
- Creencias sobre el margen de actuación terapéutica

VALORES Y VIVENCIA

- Aspectos más importantes de la enfermedad
- Aspectos más importantes de la atención
- Preocupaciones, miedos, desazones
- Actitudes sobre la enfermedad y la salud
- Antecedentes de duelos y la vivencia de los mismos
- Antecedentes de afrontamiento
- Expectativas

DECISIONES CONCRETAS

- Situaciones concretas previsibles
- Condiciones de adecuación del esfuerzo terapéutico
- Lugar prioritario de atención en los momentos de crisis o descompensación
- Solicitudes especiales
- Designación de representante
- Aspectos relacionados con la despedida, el funeral…

Modelo de Planificación de Decisiones Anticipadas del Instituto Catalán de Oncología

https://vimeo.com/628936517/572522000f

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Original Article

Spanish Cross-Cultural Adaptation and Psychometric Properties of the Advance Care Planning Self-Efficacy: A Cross-Sectional Study

Cristina Lasmarías, RN, MA, PhD(c),[1,2,*] Mireia Subirana-Casacuberta, RN, MSN, PhD,[3,4,**] Núria Mancho, MSc,[5] and Amor Aradilla-Herrero, RN, MSc, PhD[6,***]

Abstract

Background: Perceived self-efficacy in advance care planning (ACP) is frequently used to measure the impact of ACP programs for professionals responsible for advanced chronic patients. A validated ACP Self-Efficacy (ACP-SE) scale is not currently available in Spanish.
Objective: To culturally adapt and validate Baughman's ACP-SE scale into Spanish (ACP-SEs).
Methodology/Design: An instrumental study was performed in two phases: (1) cultural adaptation of the ACP-SE scale and (2) psychometric properties measurement.
Setting/Participants: The survey was sent to 5785 professionals: physicians, nurses, psychologists, and social workers, members of scientific associations in the areas of primary care, geriatrics, and palliative care in Catalonia, Spain.
Results: Five hundred thirty-eight questionnaires were obtained, respondents were physicians (69.0%) and nurses (28.4%) and mean age was 47 years (standard deviation [SD] = 10.1). Most were women (79.6%), 68% had >15 years of professional experience, and 80.7% worked in primary care. Internal consistency was high (Cronbach's alpha = 0.95) and showed a unidimensional structure explaining 56.2% of total variance. Mean score was 67.37 (SD = 16.1). Variables associated with greater self-efficacy were previous training ($t = -3.23$, df = 273.76, $p = 0.001$), previous participation in ACP processes ($t = -6.23$, df = 521, $p < 0.001$), and membership in geriatric or palliative care scientific association ($p < 0.001$). ACP-SEs positively correlated to other compared scales.
Conclusion: The ACP-SE scale demonstrates adequate psychometric properties. This is the first self-efficacy scale for ACP in Spanish. It should facilitate a better understanding of implementation processes related to ACP programs for professionals involved in caring for patients with advanced diseases.

Keywords: advance care planning; psychometrics; reproducibility of results; self-efficacy

Publicación 2

Lasmarías C, Subirana-Casacuberta M, Mancho N, Aradilla-Herrero A. Spanish Cross-Cultural Adaptation and Psychometric Properties of the Advance Care Planning Self-Efficacy: A Cross-Sectional Study. J Palliat Med. 2021 Jun 18. DOI: 10.1089/jpm.2020.0653. *Impact factor; 2.947 (2020); Quartil: Q2*

Fase 1: traducción y contratraducción

1 Nada capaz – 5 Totalmente capaz

1. Encontrar el tiempo para hablar con el paciente sobre su pronóstico, preferencias y plan de atención	☐1	☐2	☐3	☐4	☐5
2. Determinar el grado de información que / cuánto desea conocer el paciente sobre su pronóstico	☐1	☐2	☐3	☐4	☐5
3. Determinar el nivel de implicación que el paciente desea en la toma de decisiones	☐1	☐2	☐3	☐4	☐5
4. Determinar la persona (de su entorno afectivo) que el paciente desearía involucrar en la toma de decisiones	☐1	☐2	☐3	☐4	☐5
5. Ofrecer el grado de información deseado y la orientación necesaria para ayudar al paciente en la toma de decisiones	☐1	☐2	☐3	☐4	☐5
6. Describir los pros y contras de los diferentes tratamientos de soporte vital	☐1	☐2	☐3	☐4	☐5
7. Determinar los deseos específicos de los pacientes en cuanto a los tipos de tratamientos médicos	☐1	☐2	☐3	☐4	☐5
8. Discutir y negociar los objetivos y planes de tratamiento individualizado con el paciente	☐1	☐2	☐3	☐4	☐5
9. Asegurar que, en lo que bajo tu responsabilidad respecta, las preferencias del paciente serán respetadas	☐1	☐2	☐3	☐4	☐5
10. Asegurar que las preferencias del paciente serán respetadas si el paciente es hospitalizado	☐1	☐2	☐3	☐4	☐5
11. Hablar con el paciente sobre cómo cumplimentar el documento de voluntades anticipadas	☐1	☐2	☐3	☐4	☐5
12. Determinar con el paciente en qué momento deberían modificarse los objetivos de la atención	☐1	☐2	☐3	☐4	☐5
13. Re-evaluar los deseos del paciente en el momento en que se requiere un cambio en los objetivos de la atención	☐1	☐2	☐3	☐4	☐5
14. Hablar abiertamente con el paciente sobre dudas o incertidumbres, en caso de que las haya	☐1	☐2	☐3	☐4	☐5
15. Educar y clarificar con el paciente cualquier información / creencia errónea sobre la enfermedad o el pronóstico	☐1	☐2	☐3	☐4	☐5
16. Responder de forma empática a las preocupaciones del paciente y su familia	☐1	☐2	☐3	☐4	☐5
17. Comunicar malas noticias al paciente y su familia	☐1	☐2	☐3	☐4	☐5
18. Involucrar al paciente en la conversación sobre planificación de decisiones anticipadas	☐1	☐2	☐3	☐4	☐5
19. Registrar adecuadamente las decisiones y el plan de atención acordado a lo largo de la PDA	☐1	☐2	☐3	☐4	☐5

Lasmarías C, Subirana-Casacuberta M, Mancho N, Aradilla-Herrero A. Spanish Cross-Cultural Adaptation and Psychometric Properties of the Advance Care Planning Self-Efficacy: A Cross-Sectional Study. J Palliat Med. 2021 Jun 18. DOI: 10.1089/jpm.2020.0653.

Escala ACP-SEs de Lasmarías et al. de 19 ítems

International Journal of *Environmental Research and Public Health*

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Article

Primary Care Professionals' Self-Efficacy Surrounding Advance Care Planning and Its Link to Sociodemographics, Background and Perceptions: A Cross-Sectional Study

Cristina Lasmarías [1,2], Amor Aradilla-Herrero [3,*], Cristina Esquinas [4,5], Sebastià Santaeugènia [2,6], Francisco Cegri [7,8], Esther Limón [9,10] and Mireia Subirana-Casacuberta [11,12]

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Keywords: advance care planning; primary care; self-efficacy

Publicación 3

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Análisis multivariado

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Supplementary

Table S1. Supplemental table. Multivariate analysis. Logistic regression model (dependent variable ACP-SEs[1] >75 points).

	OR	IC95%	*p-value*
(Intercept)	0.06	0.03 – 0.11	**<0.001**
Have you participated in an ACP process with a patient? (Yes)	1.70	1.02 – 2.84	**0.043**
The ACP process contributes to improving the patients' quality of life (>8 points)	1.93	1.16 – 3.25	**0.013**
ACP facilitates knowledge of patients' values and preferences (>8 points)	2.24	1.12 – 4.76	**0.028**
Do you consider yourself to be sufficiently trained to carry out ACP processes? (≥ 8 points)	3.98	2.37 – 6.74	**<0.001**

[1] ACP-SEs= Advance Care Planning Self Efficacy Spanish; *p*-values < 0.05; Statistically significant differences have been marked in bold

Table S2. Supplemental table. Statistical probability of showing a condition and scoring the ACP -SEs [1] >75 points

Having participated in an ACP process + ACP contributes to improving patients' quality of life >8 points + ACP facilitates knowledge of preferences and values >8 points + Considers him/herself to be sufficiently trained to carry out ACP processes >8 points	68.00%

[1] ACP-SEs= Advance Care Planning Self Efficacy Spanish.

- **Haber participado previamente en procesos de PDA**
- **Considerarse suficientemente bien formado**
- **Creer que la PDA contribuye a mejorar la calidad de vida de los pacientes**
- **La PDA facilita el conocimiento de sus preferencias y valores**

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Dificultades de las enfermeras de atención primaria en los procesos de planificación anticipada de las decisiones: un estudio cualitativo☆

Nani Granero-Moya[a,*], Antonio Frías-Osuna[b], Inés M. Barrio-Cantalejo[c] y Antonio Jesús Ramos-Morcillo[d]

Editorial

Planificación de decisiones anticipada y barreras para su implementación

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Exploración de los valores y deseos de pacientes con enfermedad crónica avanzada y con enfermedad crónica compleja. Conversaciones acerca del final de la vida

Christian Villavicencio-Chávez*[1], Cristina Garzón-Rodríguez[2], Jesús Vaquero-Cruzado[3], Enric Grácia[4], Anna Torrents[4] y Pilar Loncán[5]

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ORIGINAL

La planificación compartida de la atención en personas con enfermedad oncológica en un instituto monográfico de cáncer: estudio descriptivo retrospectivo

Cristina Lasmarías Martínez[1,2*], Candela Calle Rodríguez[1], Anna Esteve Gómez[3] y Jordi Trelis Navarro[1]

Med Paliat. 2020;27(3):267-268
Medicina Paliativa
www.medicinapaliativa.es
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CARTAS AL DIRECTOR

Planificación compartida de la atención: la COVID-19, ¿una oportunidad?

Cristina Lasmarías Martínez[1*], Tayra Velasco Sanz[2], Virginia Carrero Planes[3], Nani Granero-Moya[4], en nombre de la Asociación Española de Planificación Compartida de la Atención*

Preparémonos para la peor, esperemos lo mejor

Respecting Choices. 2018

Qué me llevo de esta sesión

https://jamboard.google.com/d/1a5ifmlpRib_FKZj2s6YBvi3W70TrjEaNpwQeb4Yi_DA/edit?usp=sharing

1ª Jornada de Planificación Compartida de la Atención
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