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Shared decision-making in Spain in 2022: An updated revision of the current situation

Partizipative Entscheidungsfindung in Spanien im Jahr 2022: ein Bericht zum aktuellen Stand

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ABSTRACT

In Spain, there is not a national strategy to promote shared decision making (SDM) in clinical practice, and it is still not a requisite for improving the quality of health services, in either the legal norms or professionals' educational curricula. However, several national strategies in specific health areas increasingly include the principles of person centred care (PCC) and SDM into their objectives, promoting patients' empowerment and activation. Furthermore, several institutions continue to develop Patient Decision Aids (PtDAs) and other resources to facilitate patients' involvement in their own care; training programs for professionals; links between PtDAs and clinical practice guidelines; as well as interventional studies assessing the impact of PCC and SDM interventions in clinical practice. Initiatives to involve patients in health research design and health technology assessment are also being developed. We describe an update of the current state of research, policy and implementation of SDM after five years of substantial advances in Spain. Many challenges remain regarding national and regional policies on PCC and SDM, implementation of SDM in real practice and educational curricula, development of quality indicators and evaluation procedures.

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ZUSAMMENFASSUNG

In Spanien gibt es keine nationale Strategie zur Förderung der gemeinsamen Entscheidungsfindung (SDM) in der klinischen Praxis, und es ist immer noch keine Voraussetzung für die Verbesserung der Qualität der Gesundheitsdienste, weder in den gesetzlichen Normen noch in den Lehrplänen der Fachkräfte. Mehrere nationale Strategien in bestimmten Gesundheitsbereichen beziehen jedoch zunehmend die Prinzipien der personenzentrierten Versorgung (PCC) und SDM in ihre Ziele ein, um die Selbstbestimmung und Aktivierung der Patienten zu fördern. Darüber hinaus entwickeln mehrere Institutionen weiterhin Patientenentscheidungshilfen (Patient Decision Aids, PtDAs) und andere Ressourcen, um die Einbeziehung der Patienten in ihre eigene Versorgung zu erleichtern; Ausbildungsprogramme für Fachleute; Verbindungen zwischen PtDAs und Leitlinien für die klinische Praxis; sowie interventionelle Studien zur Bewertung der Auswirkungen von PCC- und SDM-Interventionen in der klinischen Praxis. Initiativen zur Einbeziehung von Patienten in die Gestaltung

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der Gesundheitsforschung und die Bewertung von Gesundheitstechnologien werden ebenfalls entwickelt. Wir beschreiben einen aktuellen Stand der Forschung, Politik und Umsetzung von SDM nach fünf Jahren erheblicher Fortschritte in Spanien. Viele Herausforderungen bleiben bestehen: in Bezug auf die nationale und regionale Politik zu PCC und SDM, die Umsetzung von SDM in der Praxis und die Lehrpläne, die Entwicklung von Qualitätsindikatoren und Bewertungsverfahren.

The Spanish National Healthcare System: potential advantages and disadvantages for person centred care and shared decision making implementation

The Spanish National Health System (Spanish NHS) is publicly funded, universal model of care, and decentralised in its management and financing, with a macro level of policy coordination by the Spanish Ministry of Health. The right to health protection is guaranteed in article 43 of the Spanish Constitution for all Spanish citizens. The General Health Law of 1986 established the principles and criteria for constitutional application. The provision and financing of health care depend on the Regional Health Authorities, and the Directorate General of the common portfolio of services of the NHS and Pharmacy (DGPSPh) of the Spanish Ministry of Health is the national organisation responsible for coverage approval of health technologies [1].

Mechanisms for introducing health technologies (such as patient decision aids) in Spain are informed by the Spanish Network of Agencies for Assessing National Health System Technologies and Performance (RedETS; redets.sanidad.gob.es) and the Spanish Network for the Evaluation of Medicines in the National Health System (REvalMed NHS; aemps.gob.es). RedETS is the organisation responsible for appraising the safety, effectiveness, cost-effectiveness, organisational aspects, and legal, ethical, and environmental issues of all non-pharmaceutical technologies [2]. REvalMed is a state agency linked to the Ministry of Health, responsible for assessing the quality, safety, and efficacy of medicines before market access of pharmacological technologies.

The public nature of the Spanish NHS ensures the availability of quality, equitable and accessible healthcare services, and could be an advantage in order to effectively implement person centred care (PCC) and shared decision making (SDM) policies and procedures at all levels of the Spanish NHS. Furthermore, the strength of the Spanish primary care system based on the existence of a structured system as well as a comprehensive package of benefits for an effective continuity of care across levels [3], may facilitate the successful adoption of SDM and patients' involvement. However, the decentralised responsibilities for healthcare to lower levels of government and administrations in Spain could result in a heterogeneous introduction of SDM across regions, duplicated efforts and less efficiency in the development of SDM resources and technologies, implementation protocols and evaluation procedures.

National strategies and policies for person centred care and shared decision making

The Law for Patient Autonomy and Health Documentation and Information-Related Rights and Obligations (41/2002) [4], that incorporated the principles of the Oviedo Convention on Human Rights and Biomedicine [5], regulates matters such as the right to health information, informed consent, patient's right to autonomy, health documentation, clinical records, and other clinical information. However, two decades later there is still a lack of a national strategy for the promotion and implementation of PCC and SDM in the Spanish NHS.

Nonetheless, national strategies for specific health areas have indeed included explicit mentions to SDM. For instance, the primary and community care strategy [6] have among its objectives improving the decision-making capacity of individuals, families and communities, to promote active users and to achieve a lasting alliance with the population based on SDM. Other examples are strategic plans for different health conditions or users of the health system [7–9], as well as the strategy for digital health, information and innovation [10].

Although national systems and standards for monitoring the implementation of the principles of PCC and SDM are still lacking in the Spanish context [11], relevant steps have been taken to assess PCC of primary care services. Value-based payment systems are also used to incentivise healthcare professionals to implement PCC in the healthcare system [12].

Patient and public involvement in research and development of person centred care and shared decision making

Incorporating the perspective of users, such as patients and their families or healthcare professionals, from the earliest phases of research design and development, may ensure aspects such as the relevance, appropriateness and acceptability of SDM interventions, including PtDAs and other support tools, are achieved and implemented [13–17]. In Spain, within the notion of patient involvement and the framework of user-centred design [18], progress is increasingly being made in the incorporation of participatory and integrative methodologies from the perspective of users and other relevant actors [13,19]. The use of methodological resources such as co-creation in the initial design phases or the identification of information and research needs by the relevant actors legitimises the process from the beginning [20,21].

Likewise, the Spanish RedETS has developed a Patient Involvement Strategy aimed to promote patients' participation from the first phases of the elaboration of Health Technologies Assessment reports [22]. This strategy was built by integrating results from a literature review, semi-structured interviews with health technology assessment managers and researchers with experience in patients' involvement, a consultation to patient organisations, and a Delphi process among the members of the RedETS Governing Council [14]. The strategy used involvement as an inclusive concept with three levels of participation: communication, consultation, and engagement. The objective of the strategy is to increase impact and understand the appropriate role of patient-based evidence [22,23].

Other examples of the use of more participatory and inclusive design methodologies, include studies aiming to identify patients' information needs, as well as research priorities from the perspective of patients, relatives or healthcare professionals [24–26]. Additionally, different initiatives have recently used co-creation strategies to promote patient empowerment among healthcare users with different health conditions [27–30].

SDM research

Currently, there are still no public or private funding programs specifically aimed at SDM/PCC research. To obtain funding, research projects in this area must compete in general funding calls with other projects of a clinical and epidemiological nature.

The development and assessment of PtDAs continues to be the most active line of research. New studies and research protocols have been published evaluating PtDAs for patients with rheumatoid arthritis [31], hip osteoarthritis [32], hormonal contraception [33], generalised anxiety [34] or the elderly with chronic diseases and polypharmacy [35]. Other studies have developed communication tools [36] and support materials aimed at facilitating the application of SDM by health professionals [37], but they did not assess their effectiveness. Two recent study protocols will assess the effectiveness of risk communication in breast cancer screening (DECIDO study) [38] and the integration of decision analysis in a decision tool for thromboprophylaxis during pregnancy (DASH-TOP) [39].

The SDM-Q-9 questionnaire has recently been used to assess the perception of SDM during oncology consultations, both by patients [40,41] and physicians [42,43], showing discordant results among patients and healthcare professionals being higher in the latter. In another study, the psychometric properties of this questionnaire have been analysed in patients with multiple sclerosis [44]. The three-item scale CollaboRATE has also been validated in psychiatric outpatients [45]. Another study assessed control preferences and perceptions (Control Preference Scale) and information needs in patients with Generalised Anxiety Disorder [25].

Other initiatives assess more complex, multicomponent interventions including PCC and SDM interventions for patients or professionals [27,46]. The European project COMPAR-EU, funded by the European Commission, aims to identify and compare self-management interventions in order to develop decisions tools for promoting the empowerment of adults living with type 2 diabetes, obesity, chronic obstructive pulmonary disease and heart failure [47]. Other projects evaluate the effectiveness of a virtual community practice to improve the empowerment of patients with ischaemic heart disease (eMPODERA-2 study [48]), a person-centred intervention in young-old patients with multimorbidity and polypharmacy, aimed at improving medication appropriateness (MULTIPAP study [49]), or a multicomponent intervention to implement a clinical practice guideline (CPG) for systemic lupus erythematosus [50].

The implementation of PCC and SDM resources and procedures is still little investigated. By means of group consultation to relevant stakeholders, García-Altés et al. [11] have recently proposed a list of potential actions aimed at integrating SDM in public health services, from a macro, meso and micro perspective. Grandes et al. [16] developed an implementation strategy, collaboratively with health care providers and community-based organisations, aimed at integrating health promotion in primary and community care [16]. However, these initiatives have not still been applied in real practice. Spanish institutions also participate in the CHRODIS-PLUS European project, developing a methodological approach for implementing an integrated multimorbidity care model, which includes SDM as a core component [51]. This project does include a post-implementation phase that will provide data about its feasibility, acceptability and effectiveness.

Institutions promoting SDM and Patient Decision Aids

In Spain there are no national standards for the certification of PtDAs, although it is recommended to follow the standards of the *International Patient Decision Aid Standards* (IPDAS) Collaboration [52]. Some Health Technology Agencies included in RedETS, from regions such as Canary Islands, Catalonia, Andalusia and Madrid, have developed and implemented PtDAs for different specific conditions, making them available on their websites.

GuiaSalud (www.guiasalud.es), the CPGs library of the Spanish NHS, is working on the creation of a catalogue of PtDAs. In addition to these public institutions, several PtDAs have been developed and evaluated in research studies. Additionally, given the growing ethical interest in patient empowerment, other public and private initiatives have been promoted to provide citizens, patients, relatives and caregivers with evidence-based information, which allow them to manage their conditions in the most appropriate way and taking their preferences into account. Appendix A shows examples of some of these initiatives to promote patient or citizen empowerment and SDM in Spain.

Link between patient decision aids and clinical practice guidelines

It is necessary to facilitate the use of CPGs in SDM processes, and complement them with PtDAs in those situations in which the effective incorporation of the patient's values and preferences are especially relevant. In 2017, a systematic review of the literature and a qualitative study with in-depth interviews, carried out by RedETS aimed to collect and analyse the perceptions of experts in relation to directly link the CPGs and PtDAs [53]. Based on this previous work, a practical methodological handbook for the application of the CPG recommendations to SDM has been developed. This handbook, which is expected to be published in 2022, aims to provide a standardized methodology to integrate SDM and PtDAs into the process of developing CPG recommendations, with the ultimate goal of facilitating their use in clinical practice [54].

An example of linking PtDAs and CPGs comes from the update of a CPG for Generalized Anxiety Disorder (GAD). The Evaluation Unit of the Canary Islands Health Service (SESCS), in collaboration with GuíaSalud, has developed a PtDA, whose results will be available on the PyDeSalud platform (https://pydesalud.com/trastorno-de-ansiedad-generalizada/).

Person centred care and shared decision making in medical education and training for healthcare professionals

Education and training concerning the principles of PCC and SDM are being increasingly included as part of the curricula in medical and nursing education in Spain, especially in the primary care setting [55]. Learning experiences with undergraduate medical and nursing students and resident healthcare professionals in PCC and SDM are being incorporated into course curricula. Many of the curriculum components identified as relating to PCC and SDM involve either a general mention of PCC or SDM within module/session outlines or the inclusion of concepts linked to PCC or SDM (e.g., patient activation, motivational interviewing, patient empowerment, self-management, (digital) health literacy, communication skills, and integrated care management in PCC medical home). However, there are wide differences between universities in the way PCC and SDM are included in both professional standards and curricula. This means that the standardised and generalised incorporation of SDM and PCC into Spanish healthcare professionals' education remains a challenge.

Other relevant initiatives are being put into practice, such as short courses, workshops and summer courses. An example of this is the course offered by the Autonomous University of Madrid and the Jimenez Diaz Foundation, in collaboration with other European universities. Likewise, the initiatives promoted by the professionals of the Women's Health Institute of the Hospital Universitario Clinico San Carlos de Madrid, have set up a SDM consultation with patients on the surgical treatment of breast cancer, whereby patients can assess the available surgical options together with the multidisciplinary medical team. At a research level, there are examples of training programs for patients and healthcare professionals including the component of SDM [37,56,57].

Formal measurement of the process of shared decision making

Although the authors have not found specific information on quality indicators of SDM performance, progress has been made in the inclusion of aspects related to PCC in the evaluation of health service provision. This is the case of some Health Departments in the different Spanish autonomous regions, which have recognised the need to broaden the criteria for evaluating the quality of healthcare services. Thus, criteria such as patient empowerment and the promotion of greater citizen participation are proposed. In this regard, most Spanish hospitals have included, in their institutional policies and strategic plans, good practice guides, in which the central axis is the *humanisation of healthcare*. The main objective of these actions is to translate the postulates of PCC into practice, as it is based on the premise that this approach offers more favourable conditions for the correct implementation of SDM, both at the individual and collective level. Some examples of these strategies, in the public and private context, are the Hospital Clinic of Barcelona Strategy Plan [58], the Humanization Plan of the Junta de Andalucía [59], the Guide of Good Practices of San Juan de Dios Hospital [60], the Humanization of services in San Roque Hospitals (Canary Islands) [61], and the Humanization Plan for the Community of Madrid [62], among others.

In addition, with the above health care model focused on the humanisation, the level of excellence of healthcare has been evaluated as a starting point in relation to five areas: leadership for humanisation, management based on humanisation, PCC, the care of the professional and the humanisation of spaces. Another example of quality indicators of PCC interventions is the SPICA framework, which is integrated into the Canary Islands strategy for managing chronic diseases. This framework proposes actions and indicators to enhance integration and continuity between and across levels of care.

Collaborative projects and international networking

In 2013, the emerging Ibero-American Network for SDM (REDES, *REd Iberoamericana para la Toma de DEcisiones Compartidas en Salud*) of healthcare professionals and researchers from hospitals, health centres, health services evaluation units and universities in Latin America and the Caribbean, Spain and Portugal, was formed. The experience of expert researchers in SDM from different countries and contexts (i.e., clinical practice, research, and academia) endows the creation of this network, with a unique character. REDES aims to promote research into SDM and the creation of PtDAs, as well as their implementation in clinical practice, in order to improve health care and the satisfaction of users and healthcare professionals in the Ibero-American context. Following these objectives, REDES provides a link that facilitates the exchange of ideas among its members, in order to promote the field of research on SDM in those Spanish-speaking countries where this line of work is still unknown or is in need of support for its expansion.

Furthermore, Spanish researchers participate in various international projects that seek to promote or implement interventions for SDM. The topics addressed within the European Union are varied, such as the construction of methodological frameworks for implementing an Integrated Multimorbidity Care Model in local health systems (Joint Action CHRODIS-PLUS), the development of massive online open courses (MOOCs) to improve digital health literacy skills of European citizens as an open education initiative for all (IC-Health project), among others. Different publications report the results of these collaborations [27,28,39,51,63–65].

Challenges and future perspectives of shared decision making in Spain

The PCC and SDM model is increasingly taken in consideration in the Spanish NHS, research centres, scientific associations and patient organisations. However, the initiatives proposed are very heterogeneous in terms of their scope and implementation between the different regions, reflecting the decentralization of the Spanish health system. It is necessary to develop a national strategy specifically aimed at this model of care, which establishes general actions and implementation protocols, as well as process quality indicators.

According to Abrams et al. [66], the current Covid-19 pandemic has created both challenges and opportunities for relevant changes in delivering care, as system adaptations influence the healthcare professional-patient relationship. Although social distancing and health service reallocation can interfere with preference for an in-person visit, these measures also provide an avenue to study and implement virtual SDM processes. Communicating risk at a time of heightened uncertainty may pose a barrier to SDM engagement but provides the opportunity to foster a PCC within a more personalised context. Social media influence during the coronavirus/Covid-19-pandemic has resulted in an "infodemic" but highlights the importance of patient engagement. The pandemic has changed how we deliver care but allows us to re-evaluate common practices and enhance the effectiveness of our management strategies.

Conflict of interest

The authors declare that there is no conflict of interest.

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Lilisbeth Perestelo-Perez: Conceptualization, Methodology, Resources, Writing-Original draft preparation, Writing-Review and Editing; Visualization, Supervision; Amado Rivero-Santana: Methodology, Writing-Original draft preparation, Writing-Review and Editing, Supervision; Yolanda Alvarez-Perez: Methodology, Writing-Original draft preparation, Writing-Review and Editing, Visualization; Andrea Duarte-Díaz: Methodology, Writing-Original draft preparation, Writing-Review and Editing; Visualization; Vanesa Ramos-García: Methodology, Writing-Original draft preparation, Writing-Review and Editing; Visualization; Alezandra Torres-Castaño: Methodology, Writing-Original draft preparation, Writing-Review and Editing, Visualization; Analía Abt-Sacks: Methodology, Writing-Original draft preparation, Writing-Review and Editing, Visualization; Ana Toledo-Chavarri: Writing-Review and Editing; Pablo Alonso-Coello: Writing-Review and Editing; Carola Orrego: Writing-Review and Editing; Pedro Serrano-Aguilar: Conceptualization, Writing-Original draft preparation, Writing-Review and Editing.

Appendix A. Supplementary data

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