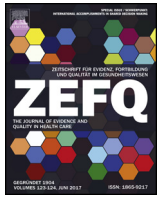


Contents lists available at [ScienceDirect](http://www.elsevier.com/locate/zefq)

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ)

journal homepage: <http://www.elsevier.com/locate/zefq>

Special Issue / Schwerpunkt

Shared decision making in Spain: Supportive policies and research initiatives, trends and directions for future

*Partizipative Entscheidungsfindung in Spanien: unterstützende Maßnahmen und Forschungsinitiativen, Trends und künftige Entwicklungen*Lilisbeth Perestelo-Perez^{1,2,3,*}, Amado Rivero-Santana^{2,3,4}, Yolanda Alvarez-Perez⁴, Pablo Alonso-Coello^{5,6}, Carola Orrego^{2,7}, Pedro Serrano-Aguilar^{1,2,3}¹ Evaluation Unit of the Canary Islands Health Service (SESCS), Tenerife, Spain² Health Services Research on Chronic Patients Network (REDISSEC), Tenerife, Spain³ Center for Biomedical Research of the Canary Islands (CIBICAN), Tenerife, Spain⁴ Canarian Foundation for Health Research (FUNCANIS), Tenerife, Spain⁵ Iberoamerican Cochrane Center, Biomedical Research Institute Sant Pau (IIB Sant Pau-CIBERESP), Barcelona, Spain⁶ Department of Clinical Epidemiology & Biostatistics, McMaster University, Hamilton, Ontario, Canada⁷ Fundació Avedis Donavedian, Barcelona, Spain

ARTICLE INFO

Article History:

Available online: 19 May 2017

Keywords:

patient decision aids
 patient involvement
 patient participation
 national health system
 shared decision making
 Spain

ARTIKEL INFO

Artikel-Historie:

Online gestellt: 19. Mai 2017

Schlüsselwörter:

Entscheidungshilfen für Patienten
 Patientenbeteiligung
 Patientenmitwirkung
 nationales Gesundheitssystem
 partizipative Entscheidungsfindung
 Spanien

ABSTRACT

Patients' rights to autonomy, information and participation in their own health care are recognized in the Spanish legal system from the early 2000's. Public institutions have progressively launched several initiatives to promote and improve patients' empowerment and self-care. However, the concept of shared decision making (SDM), although embedded in the more general concept of "active/empowered patient", usually has not been specifically advocated as an essential requisite for improving the quality of health services, either in the legal normative or the existing educational proposals. Research on SDM and the development of Patient Decision Aids (PtDAs) has increasingly grown and currently there are several of these materials available for patients with different diseases. Along with this research activity, the growing interest of patients and professionals in patient participation and SDM makes us optimistic about a gradual development of this care model in the medium term. However, there are several limitations and challenges that must be overcome in the near future. The implementation of PtDAs in clinical practice is imperative and issues such as their inclusion in clinical guidelines and electronic medical records should be encouraged. Concurrently, it is necessary to train professionals in SDM skills and the use of encounter PtDAs.

ZUSAMMENFASSUNG

Das Recht des Patienten auf Autonomie, auf Informationen in Bezug auf die eigene Gesundheitsversorgung und seine Teilhabe daran wird vom spanischen Rechtssystem seit Anfang der 2000er-Jahre anerkannt. Nach und nach haben öffentliche Institutionen mehrere Initiativen auf den Weg gebracht, welche die Stellung des Patienten durch Information, Mitentscheidung und Teilhabe (Empowerment) sowie seine Selbstfürsorge fördern und verbessern sollen. Das Konzept der partizipativen Entscheidungsfindung (PEF) ist zwar in das allgemeinere Konzept des „aktiven/befähigten Patienten“ eingebettet, wird in der Regel aber weder im Rahmen der gesetzlichen Vorgaben noch der bestehenden Bildungsangebote als wesentliche Voraussetzung für die Verbesserung der Qualität von Gesundheitsleistungen speziell gefördert. Die Forschung über partizipative Entscheidungsfindung und die Entwicklung von Entscheidungshilfen für Patienten gewinnen zunehmend an Bedeutung, und gegenwärtig sind mehrere

* Corresponding author: Lilisbeth Perestelo-Perez, PhD. Servicio de Evaluación del Servicio Canario de la Salud. Camino Candelaria, s/n. 38109. El Rosario. S/C de Tenerife, Spain.

E-mails: lilisbethp@gmail.com, lperperr@gobiernodecanarias.org (L. Perestelo-Perez).

solcher Materialien für Patienten mit den verschiedensten Krankheitsbildern verfügbar. Neben diesen Forschungsaktivitäten stimmt uns auch das wachsende Interesse von Patienten und Ärzten an partizipativer Entscheidungsfindung und an der Einbindung von Patienten in ihre Versorgung zuversichtlich, was auf mittlere Sicht die schrittweise Weiterentwicklung dieses Versorgungsmodells betrifft. Es bestehen allerdings gewisse Einschränkungen und Herausforderungen, die in naher Zukunft bewältigt werden müssen. Die Implementierung von Entscheidungshilfen für Patienten in die klinische Praxis ist unerlässlich und Aspekte wie die Berücksichtigung von Entscheidungshilfen in klinischen Leitlinien und elektronischen Krankenakten sollten gefördert werden. Gleichzeitig ist es notwendig, medizinische Fachkräfte in PEF-Fertigkeiten und im Einsatz von Entscheidungshilfen für Patienten zu schulen.

Introduction

The *Spanish National Health System (NHS)* is the agglomeration of public health services that has existed in Spain since it was established through and structured by the *General Health Law of 1986*. It creates a NHS with universal coverage of a predominantly public nature charged to the State Budget, comprising the *Health Services* of both the *General State Administration* and regional governments. Following the transfer of healthcare powers to the 17 regional governments, the legal framework was completed in 2003 with the *Quality and Cohesion of the National Health System Act*, which provides for coordination and cooperation between public health authorities to ensure the right of citizens to health protection, with the common goal of guaranteeing equal access to services, the quality thereof and citizen participation.

The improvement in the main health indicators in Spain (life expectancy and child mortality) have evolved simultaneously with improved accessibility to health services, quality of care, and advances in technology. In this context, putting the citizen at the centre of all activities and the gradual orientation of health services to satisfying their needs, favouring its autonomy by providing them with comprehensible information according to personal circumstances, are aspects increasingly recognised. The goal of this manuscript is to describe some current developments in the Spanish health care system and research on Shared Decision making (SDM).

Legislative framework

In legal terms, the *General Health Law 14/1986* covers the fundamental rights related to the principle of autonomy of users. Subsequently, the *Oviedo Agreement of 4 April 1997* (prevailing since January 2000), reviews and explains patient rights, and together with the *Law of Patient's Autonomy 41/2002*, regulates the rights and duties of patients as regards clinical information and documentation.

These laws explicitly set out the rights of patients to ascertain and be informed about any situation that affects them on diagnosis, prognosis, treatment alternatives, and quality of life. Prior consent of patients for any health procedure is established as an essential requirement, and their right to freely decide after they have received the appropriate information is recognised. This information, which as a general rule should be provided verbally and recorded in the clinical history, includes, at least, the purpose and nature of each intervention, as well as its risks and benefits. In addition, the right to not being informed is established, except in those cases in which interest in the patient's health prevails.

This regulation, along with other factors such as the improved population educational level, the media's increased coverage of health topics, or the better access to health information has led to a gradual change in the NHS paradigm, which at a micro- and meso-levels is beginning to recognise the need of a more patient-centred health care. Nonetheless, as described above, the current

legal framework is focused on the appropriate provision of information to the patient, but it does not explicitly include the concept of SDM between patients and health care providers. On the other hand, a favourable legal, regulatory, and ethical context is not sufficient by itself for standardised implementation of SDM in practice. Therefore, organisational, contextual, and behavioural changes in society and the NHS still need to be developed.

Institutions promoting SDM

Public institutions

Spanish public institutions have shown a growing ethical and clinical interest in patient empowerment and the use of interventions which facilitate their active participation in medical decision making. However, in line with the legal framework above mentioned, the most significant progress to date has been mainly informative and consultative, oriented to educate patients with the aim of promoting a better self-management of diseases, whereas specific initiatives or programs on SDM are still an exception. In this sense, both the NHS and regional Governments have promoted a significant development of health information materials and processes, which have facilitated access to and use of information by users. [Table 1](#) shows examples of some of these initiatives. The objective of these resources is to promote the empowerment of patients so they and their relatives and caregivers have information both from the clinic and of the services and support, which allow them to manage their diseases in the most appropriate way according to their preferences.

Examples of programs developed through these initiatives are "The Active Patient" (*Paciente Activo*), an initiative created by the "Health Schools" (*Escuelas de Salud*), aimed to teach patients and caregivers to be able to understand their illness and make appropriate decisions about it. Another initiative is the program "The Expert Patient" (*Paciente Experto*), which has been implemented in several regions to promote the role of the patient as the main responsible for her/his health care, and facilitate the skills acquisition to manage the disease, incorporate healthy lifestyles and achieve a better quality of life, in collaboration with health professionals.

More specific initiatives for the promotion of SDM, such as the development of PtDAs, are being promoted by the health departments of several regions and incorporated into their portfolio of services. In the last ten years, the *Ministry of Health, Social Services and Equality* has financed the development and validation of some PtDAs by regional *Agencies for Health Technology Assessment (HTA)* such as the *Andalusian HTA unit (AETSA)*, the *Canary Island Department of Health Services Evaluation (SESCS)*, and the former *HTA Unit Lain Entralgo* in Madrid.

In this context, two web platforms are worth mentioned: *PyDe-Salud* (www.pydesalud.com) (short for *Participa y decide sobre tu salud* – "Participate and decide on your health") is a resource elaborated by the SESCO in order to promote citizen participation in healthcare at national level. It is aimed at people with chronic

Download English Version:

<https://daneshyari.com/en/article/5123573>

Download Persian Version:

<https://daneshyari.com/article/5123573>

[Daneshyari.com](https://daneshyari.com)