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Shared decision making in Argentina in 2017

Partizipative Entscheidungsfindung in Argentinien im Jahr 2017



Mariela Barani^{1,*}, Karin Kopitowski^{1,2}, Carolina Carrara¹, María Victoria Ruiz Yanzi¹

¹ Department of Family and Community Medicine, Hospital Italiano de Buenos Aires, Argentina

² Research Department, IUHI, Hospital Italiano de Buenos Aires, Argentina

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ABSTRACT

Argentina is a high-middle income country located in Southern South America with an estimated population of 44 million inhabitants. The epidemiological profile of the population is characterised by an increase of non-communicable diseases. The health system is heterogeneous, fragmented and loosely integrated. There are no unified research agenda or government initiatives encouraging the implementation of and research on shared decision making (SDM). Progress has been made lately to respect patient autonomy through the enactment of the 'Patients' Rights Act', which expressly enshrines the right of patients to get information as a key element of decision-making.

To our knowledge, the team at the Department of Family and Community Medicine of the Hospital Italiano de Buenos Aires is the only one working on shared decision making in Argentina. This department carries out research, medical undergraduate and graduate training, and clinical practice implementation activities through strategies aimed at professionals and patients alike.

We face some challenges regarding SDM, such as: 1) the fragmentation and the heterogeneity of the local health system; 2) we are a small group of people working on this topic who, simultaneously, have care, management, teaching and research responsibilities; 3) we have no government support and project funding is scarce; 4) due to the geographic location of the country, we must make a great effort in order to attend events on the state of the art in SDM.

Given the current state of our health system, we believe the government is not likely to encourage, implement or research on SDM in the short term. Our group will continue to work on the local initiative and also to instil it in other interested groups.

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ZUSAMMENFASSUNG

Argentinien mit geschätzt 44 Millionen Einwohnern liegt im Süden Südamerikas und gehört zu den Ländern mit mittleren bis hohen Einkommen. Was die Gesundheit der Bevölkerung betrifft, so zeichnet sich das epidemiologische Profil durch einen Anstieg nichtübertragbarer Erkrankungen aus. Das Gesundheitssystem ist heterogen, fragmentiert und nur lose integriert. Es gibt weder eine einheitliche Forschungsaufgabe noch staatliche Initiativen zur Förderung der Implementierung von partizipativer Entscheidungsfindung und diesbezüglicher Forschung. Durch das Inkrafttreten des Patientenrechtegesetzes ("Ley de derechos de los pacientes") wurden in jüngster Zeit deutliche Fortschritte im Hinblick auf die Achtung der Patientenautonomie erzielt. In diesem Gesetz ist das Recht der Patienten auf Information und Aufklärung als Schlüsselement der Entscheidungsfindung ausdrücklich verankert worden.

Nach unserem Wissensstand ist die Abteilung für Allgemein- und Familienmedizin am Hospital Italiano de Buenos Aires die einzige in Argentinien, an der partizipative Entscheidungsfindung (PEF) derzeit thematisiert wird. Diese Abteilung forscht, bildet Studierende der Medizin im Grund- und Hauptstudium aus und widmet sich der Implementierung von PEF in der klinischen Praxis unter Einsatz von Strategien, die gleichermaßen auf Fachkräfte wie auch Patienten abzielen.

* Corresponding author: Mariela Barani, Department of Family and Community Medicine, Hospital Italiano de Buenos Aires, Argentina.
E-mail: marielabarani@gmail.com (M. Barani).

Bei der Implementierung von partizipativer Entscheidungsfindung begegnen wir verschiedenen Herausforderungen: 1) der Fragmentierung und Heterogenität im örtlichen Gesundheitswesen; 2) dem Umstand, dass das Team, das sich mit diesem Thema befasst, nur aus wenigen Mitgliedern besteht, die gleichzeitig in der medizinischen Versorgung, im Management sowie in Lehre & Forschung tätig sind; 3) dass wir von Regierungsseite keine Unterstützung erhalten und dass die Mittel zur Finanzierung von Projekten knapp sind; 4) dass die Teilnahme an Veranstaltungen zum aktuellen Stand der partizipativen Entscheidungsfindung aufgrund der geografischen Lage unseres Landes mit großen Aufwand verbunden ist.

Angesichts des aktuellen Zustands des Gesundheitswesens in unserem Land halten wir es für eher unwahrscheinlich, dass die Regierung die Umsetzung von partizipativer Entscheidungsfindung oder Forschung auf diesem Gebiet in naher Zukunft fördern wird. Unsere Gruppe wird diese lokale Initiative weiter fortführen, auch mit dem Ziel, andere interessierte Gruppen anzusprechen.

Background of the health system

The Argentine Republic is an upper-middle income country [1] located in Southern South America. It is divided into 23 provinces and an autonomous city (Autonomous City of Buenos Aires) for administration purposes, with big socio-economic differences among them. By 2010 Argentina had a population of 40.1 million inhabitants [2] (49% male and 51% female). The estimated population in 2017 is approximately 44 million people [3]. Around 92% of the population lives in urban areas and one third lives in the metropolitan area of Buenos Aires, which also accounts for 40% of the GDP (gross domestic product). Regarding the structure of the population, the population is visibly ageing. The ratio of elderly people went from 2.5% in 1895 to 3.9% in 1947 and 10% in 2010.

The health of Argentines has improved considerably in the past twenty years as they now live longer and better. The epidemiological profile is characterised by a growing prevalence of non-communicable diseases [4]. However, there is a huge gap among the provinces. If we take, for instance, maternal mortality, while its rate in the City of Buenos Aires in 2015 was lower than 2 per 10,000 live births, in the northern provinces of the country the rate was somewhere between 10 and 15, according to the province [5]. Similarly, in the areas with a higher per-capita income, child mortality is 6.4 per 1,000 live births, while it is 12.4 in the poorest provinces [6].

Healthcare in Argentina has very unique features, so it is difficult to talk of a single health system. Multiple health financing systems –loosely integrated and internally fragmented— coexist, compete and overlap in Argentina: the public sector, the compulsory social security sector (*obras sociales* or union health insurance providers) and the private sector [7,8].

The public sector comprises the provincial and national administrative structures at the ministry level and the network of public hospitals and healthcare centres that provide free care to any person that requires so (usually people without social security who have no means), and is financed through tax revenues. The compulsory social security sector is structured around three types of social security institutions: 1) the national *obras sociales*, around 270 institutions organised by economic sector, managed by the workers' unions and coordinated by a national agency (Health Services Superintendence); 2) the provincial *obras sociales*, 24 institutions providing health insurance to the civil servants of each province; and 3) the Comprehensive Medical Care Plan of the National Institute of Social Services for Retirees and Pensioners, which provides coverage to retirees from the national welfare system and their families.

The private sector includes: a) professionals providing independent services to private patients insured by specific union health insurance providers or private health insurance systems; b) healthcare facilities, also hired by the union health insurance providers; and c) voluntary health insurance companies called private health insurance providers. Approximately 6% of the population has

healthcare coverage through individual contributions to one of the 150 private health insurance providers.

The social security system can be described as broad in terms of coverage and segmented in terms of the number of funds involved, with increasing transfer of risk to the providers, in a clear separation between insurance functions and delivery functions. Legislation passed in recent years moves towards a system with greater concentration of funds, and mainstreaming of a mandatory medical plan financed through cross-subsidising among people with different incomes and risks. However, the employment crisis reduces the total financing sources of the system, which impacts the funding of the provider model.

Legislative efforts to get shared decision making implemented in the Argentine health system

Medical practice has suffered dramatic changes in past decades due to several factors: the advancement of technology, the enactment of laws enshrining the right to health, and the proliferation of patients' rights, among others. The doctor-patient-family relationship is based on the paternalistic model, but is currently adapting to the paradigm shift as reflected in the national legislation. The principle of free will has been legally reflected by the right to personal self-determination. In light thereof, the protection of the human right to health needs to be enshrined in laws enabling the adoption of healthcare-related informative and documentary measures. The importance of patients' rights in this context, as the pivotal element of medical relationships, has been made clear by international organisations like the World Health Organisation, the United Nations, the European Union, and the Council of Europe, among others. They have adopted declarations and passed legislation and protocols in that regard.

Law 26.529, better known as the '*Patients' Rights Act*', is in force in Argentina; it is a first step –necessary and meaningful— towards the protection and enforcement of the right to health [9]. This law expressly provides for the patients' right to receive information as a key element in decision-making, especially at times like the present when patients are leaving behind the role of passive subjects in the doctor-patient relationship and becoming the lead when it comes to deciding on their own bodies. The enactment of this law allows for behaviours so far governed almost exclusively by ethical rules to become enforceable, but there are as well individual and other behaviours of interest to the society that require regulation in order to prevent the excessive court action of late. In the future, upon a conflict of opinions or values between the healthcare team and the patient regarding the performance —or not— of a given procedure, precedence shall be given to the patient's will and decision as patients are free and autonomous beings.

From an information standpoint, patients lack technical and scientific knowledge about their condition, the diagnostic or therapeutic procedures at hand, the risks and benefits involved, the

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