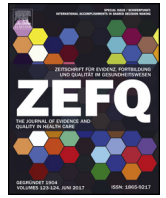




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### Patient-centred care and shared decision making in Chile: Rising momentum for progress and implementation in clinical practice



#### *Patientenzentrierte Versorgung und partizipative Entscheidungsfindung in Chile: richtiger Zeitpunkt für Fortschritt und Implementierung in die klinische Praxis*

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#### ABSTRACT

The Chilean legislation establishes that patients have rights and responsibilities in regards to their health-care. This is an important statement as it declares that people must be informed and become actively involved in their care; meanwhile, the health system needs to coordinate the provision of personalised and effective services. Although patient-centred care (PCC) and shared decision making (SDM) are relatively new concepts in Chile, the country is experiencing an interesting political momentum to create more interventions to achieve PCC and SDM and explore clinical implementation. Currently, research efforts in Chile have focused on better understanding the state of the art related to both concepts and how new clinical approaches could help to operationalize them.

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#### ZUSAMMENFASSUNG

In der chilenischen Gesetzgebung ist festgelegt, dass Patienten Rechte und Pflichten in Bezug auf ihre Gesundheitsversorgung haben. Dies ist ein wichtiges Statement, als darin festgestellt wird, dass Patienten informiert werden müssen und aktiv an ihrer medizinische Versorgung zu beteiligen sind; inzwischen gehört es zu den Aufgaben des Gesundheitssystems, die Bereitstellung personalisierter und effektiver Gesundheitsleistungen zu koordinieren. Obwohl die Konzepte der patientenzentrierten Versorgung und der partizipativen Entscheidungsfindung für Chile vergleichsweise neu sind, entfaltet sich im Land derzeit eine interessante politische Dynamik, wenn es darum geht, eine zunehmende Anzahl von Interventionen zu entwickeln, um das Ziel einer patientenzentrierten Versorgung und partizipativen Entscheidungsfindung zu erreichen und ihre klinische Implementierung zu untersuchen. Aktuell konzentrieren sich die Forschungsanstrengungen in Chile darauf, zu einem besseren Verständnis des derzeitigen Entwicklungsstandes dieser beiden Konzepte zu gelangen und zu erforschen, wie neue klinische Ansätze dabei helfen können, sie zu operationalisieren.

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## The Chilean health care system

Since 2010, the Republic of Chile has become a member of the elitist Organisation for Economic Co-operation and Development (OECD). Chile is a high-income South American country that borders with Peru, Bolivia and Argentina. There are around 17 million inhabitants, most of them (40%) living in the Metropolitan Region of Santiago. Most of the population live in urban centres with only 15% living in rural areas [1]. The gross domestic product based on purchasing-power-parity per capita reached \$24.710 USD in 2016 [2]. The country is divided into 351 municipalities grouped into 15 regions where each municipality is accountable for the publicly funded primary healthcare needs of their population [3].

The healthcare system in Chile is mixed with primarily publicly funded (FONASA) and private (ISAPRE) systems that are characterized by segmentation. Although public and private sectors coexist, they are criticized for insufficient collaborations. According to the *Survey of National Economic and Social Characteristics (CASEN)* in 2013, 95% of the total population in Chile was entitled to any healthcare provision. In fact, less than 5% of the population reports no healthcare provision at all; compared to around 8% in 2003. Of those entitled, 78.3% belonged to the public system, 14.2% to the private system, and 3% to the military or other healthcare system (e.g. international health insurance) [1]. The combination of public and private sector contributes towards paternalistic biomedical approaches of care with little or no patient involvement worsening health inequalities among patients throughout the country [4].

Over the last three decades, Chile has faced a rapid increase in chronic conditions occurring in adults and the elderly [5,6]. It has experienced deep economic, demographic, and geographical changes with consequential improvement in the health status of the population [7]. Much of the achievements in health indicators have been attributed to Chile's investment in large public health policies [8] (e.g. *Chile Crece Contigo Policy*, which focuses on early child development [9]). Although Chile has shown improvements on global health status, not all socioeconomic groups have benefited from the described developments in the same proportion. There are significant differences in the health status of the Chilean people when comparing the type of healthcare system - either public or private - geographical location, gender, household income, and age [10,11]. For instance, Chilean studies that have used the duration of formal education as a rough indicator of socioeconomic level indicated that there is a higher risk of death in the most disadvantaged socioeconomic groups [1].

### Political and legislative efforts to promote patient participation in healthcare

For the purpose of this article, we have reviewed four major milestones in the policy development process in Chile. Each one of them depicts a variable consideration of shared decision making (SDM); the first three are vertically-oriented (i.e. top-down, from the authority towards the population, and have considered the use of evidence and the voice of the society through formal, structured processes) and the last one bottom-up (from the community/civil society towards the authority).

The first one is the *Chilean Health Reform* proposed in 2000 and implemented in 2003 [12]. Through this Reform, the participatory approach was introduced in Chile. One of the key elements of this reform was that it placed patients at the centre of the care while focusing on their rights, and promoting patient participation in healthcare [13]. The reform intended to reduce health inequalities and perceived health inequities across the country over time [14] and was based on three fundamental values: a) equity in access to healthcare; b) effectiveness in interventions designed to

promote, preserve and restore health; and c) efficient use of available resources.

The second milestone is the 2006 law entitled "*Rights and responsibilities of people when engaging in their healthcare*" [15]. In addition to recognizing the dignity and autonomy of each person, this law also makes explicit the control everyone can have over their health and related decisions. The bill states that, for health decisions, physicians should provide verbal information to patients that will allow them to participate in making the decision. In the case of procedures or surgeries where there is a chance of causing harm or secondary effects, this choice should be recorded in a written consent form.

The third milestone is the progressive interest of Chileans in promoting service users' participation in their care. This could be identified in the development of the latest Sanitary Objectives described in the *National Health Plan* for the decade 2011–2020, and its first draft which was shared for general consultation and public discussion [16]. This Health Plan states, "There is no better doctor than oneself". This statement introduced the idea of involving users in their healthcare to improve both satisfaction and quality of care. This is also stated in one of the objectives of the *Chilean Health Plan* that aims to promote a more horizontal relationship between patients and health professionals [17]. Consequently, sharing information with patients is a fundamental requirement, as it is stated in the Chilean law [15]. According to the *Superintendence of Health*, the Chilean patients find that receiving information that is clear, continuous, detailed and participative, it is a key dimension to feeling respected and dignified by the health team [18]. However, the Chilean Health Policy still lacks a clear statement on how to involve people and let them participate in their healthcare. Clarifying this could help to improve patients' satisfaction with healthcare services [18].

Finally, a fourth milestone is a social movement that has been led by media figures who were advocating for the health rights of a famous TV journalist called Ricarte Soto who was experiencing a rare and catastrophic disease. This revolutionary social movement promoted the implementation of the "Ricarte Soto policy" [19]. This law protects a small and bounded budget from the central government to cover a unique number of so-called "rare" or "infrequent" diseases like some types of cancer of immunological conditions that the previous Health Reform did not cover. This has been a completely different decision making process compared to the Health Reform or the Sanitary Objectives, because it was raised by an influential person from the national television and mobilized a large proportion of society to create this new law. Most of the country sympathized with this person and, through telling his story created a massive social movement that led to this new law approved after he died.

### Research agenda on SDM in Chile

Within the *Chilean Ministry of Health*, several departments conduct health research on topics that range from clinical trials to public health. In 2001 and as recommended by the Health Objectives 2000-2010, there was a mandate to improve relationships between health research and governmental needs. Consequently, a partnership between the *Ministry of Health and National Commission for Scientific and Technological Research (CONICYT)* was established in 2004. This partnership aimed to deliver an annual economic contribution to a new fund called *National Health Research and Development Fund (FONIS)*. From 2004 to 2009, 154 projects were funded through FONIS in three areas: clinical care, public health, and psychosocial care. The projects were awarded to 48 institutions with an investment of approximately \$6.8 million USD. However, none of the funded projects were on SDM.

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