Available online at www.sciencedirect.com

www.elsevier.de/zefq

Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ) 105 (2011) 254–258

Shared decision making in Chile: supportive policies and research initiatives

Paulina Bravo[1,2,*], Báltica Cabieses[3], Claudia Bustamante[1], Solange Campos[1], Dawn Stacey[4]

[1]School of Nursing, Faculty of Medicine, Pontificia Universidad Católica, Santiago, Chile
[2]School of Medicine, Cardiff University, United Kingdom
[3]School of Nursing, Universidad del Desarrollo, Santiago, Chile
[4]School of Nursing, Faculty of Health Sciences, University of Ottawa, Canada

Summary

What about policy regarding SDM?
Since 1999, there has been a small but growing interest by academics, the government, and society as a whole in strengthening patients' and professionals' involvement in shared decision making (SDM). Two governmental policy documents that indicate support for SDM are (1) Health Reform in 2003 and (2) Sanitary Objectives 2011-2020, which includes a brief section on client participation and SDM.

What about tools – decision support for patients?
Research by Chilean academics has highlighted the patients' desire to participate in health decisions and effective approaches for enhancing health professionals' skills in interprofessional SDM; however, little has been done to support this need and the work is centralised in only one academic institution. Decision support tools and coaching interventions are limited to patients considering decisions about managing type 2 diabetes.

What about professional interest and implementation?
Although there is increasing attention to studying patients' participation and involvement on their healthcare, little has been studied in relation to professionals' interest in SDM. As well, there are significant challenges for implementation of a country-wide SDM policy.

What does the future look like?
The future looks promising given the new health policies, local Chilean research projects, and international initiatives. Collaboration between health professionals, academics, and government policy makers, with public involvement needs to be strengthened in order to promote concrete strategies to implement SDM in Chile.

Key words: patient participation, shared decision making, Chile
(As supplied by publisher)

*Corresponding author. Paulina Bravo, School of Medicine, Cardiff University, UK.
E-Mail: bravop@cardiff.ac.uk (P. Bravo).

Partizipative Entscheidungsfindung in Chile: Unterstützungs- und Forschungsinitiativen

Zusammenfassung

Wie steht es mit gesetzlichen Regelungen zur PEF?
Seit 1999 ist von akademischer, staatlicher und gesellschaftlicher Seite ein insgesamt zwar geringes, aber wachsendes Interesse an der verstärkten Einbindung von Patienten und im Gesundheitswesen Beschäftigten im Rahmen der Partizipativen Entscheidungsfindung (PEF) zu verzeichnen. Zwei Regierungsinitiativen, die eine Unterstützung von PEF erkennen lassen, sind (1) die Gesundheitsreform aus dem Jahre 2003 und (2) die Hygieneziele 2011 bis 2020, die einen kurzen Abschnitt zu Klientenbeteiligung und PEF enthalten.
Wie steht es mit PEF-Instrumenten – Entscheidungshilfen für Patienten?
Die Forschungsergebnisse von chilenischen Akademikern unterstreichen den Wunsch von Patienten nach einer Beteiligung an Gesundheitsentscheidungen und nach effektiven Ansätzen zur Verbesserung der Fertigkeiten von Angehörigen der Gesundheitsberufe in interprofessioneller PEF. Bislang wurde jedoch nur wenig unternommen, um diesen Bedürfnissen nachzukommen, und die Arbeiten dazu konzentrieren sich auf lediglich eine akademische Einrichtung. Entscheidungshilfen und Coaching-Interventionen beschränken sich bislang auf Patienten, die sich mit Entscheidungen im Rahmen der Behandlung eines Typ-II-Diabetes tragen.
Wie steht es mit dem Interesse der Profession und der Implementierung?
Obwohl Untersuchungen zur Beteiligung von Patienten an ihrer Gesundheitsversorgung zunehmend Aufmerksamkeit zuteil wird, gibt es bislang nur wenige Untersuchungen zum Interesse der Ärzte an einer Partizipativen Entscheidungsfindung. Und auch die Implementierung einer landesweiten PEF-Politik stellt eine signifikante Herausforderung dar.
Wie sieht die Zukunft aus?
Angesichts der neuen Gesundheitspolitik, lokaler chilenischer Forschungsprojekte und internationaler Initiativen sieht die Zukunft viel versprechend aus. Die Zusammenarbeit zwischen den Gesundheitsberufen, Akademikern und staatlichen Entscheidungsträgern muss unter Beteiligung der Öffentlichkeit verstärkt werden, um konkrete Strategien zur Implementierung von PEF in Chile zu fördern.

Schlüsselwörter: Patientenbeteiligung, Partizipative Entscheidungsfindung, Chile
(Wie vom Gastherausgeber eingereicht)

The Chilean healthcare system

The Republic of Chile is a middle-income South American country with an intermediate level of development. There are over 16 million inhabitants with 40% living in the metropolitan region of Santiago. Most of the population live in urban centres (85%) with only 15% living in rural areas. The gross domestic product based on purchasing-power-parity per capita reached $14,982 USD in 2010 [1]. From a political-administrative perspective, 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 [2].
Over the last 30 years, Chile has experienced deep economic, demographic, and geographical changes with consequential improvement in the health status of the population [3]. For example, there has been a decline in infant and all cause mortality rates, and an increase in life expectancy. Much of these improvements have been attributed to Chile's investment in large public health policies during the last century [4]. Their situation is comparable to some high-income countries and even better than many other Latin American countries. However, Chile is currently facing an epidemiological transition towards a rapid increase in chronic conditions occurring in adults and the elderly [5,6].
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 2003, 72% of the population belonged to the public system, 16% to the private system, and 3% to the military system for individuals in the Armed Forces [7]. More importantly, 9% of the population were not attached to any health insurance.
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, and age [8]. 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 [9,10].
The *Chilean Health Reform*, proposed in 2000 and implemented in 2003, represents the most recent influence on changes occurring in healthcare. One important element of this healthcare reform is the use of international evidence for transforming major health policies. Another important element is its focus on the rights of patients by putting them at the centre of policies, promoting their participation, and empowering them [11]. The reform is intended to reduce health inequalities and perceived health inequities across the country [12] and is 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 new health reform is continuously being evaluated and currently the *Ministry of Health* is proposing the *Sanitary Objectives* for the period 2011-2020. The process for developing the Sanitary Objectives has exemplified the commitment to citizen participation in the Health Reform. For

example, the first draft was shared for general consultation and public discussion [13]. These actions were considered critical for this review of SDM in Chile.

Legislation indicating need to involve patients' in healthcare decisions

Subsequent to the *Health Reform*, in 2006 the government presented a bill of law entitled "rights and responsibilities of people when engaging in their healthcare" [14]. In addition to recognising the dignity and autonomy of each person, this bill also made 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 writing. The law states that people have the right to be informed by an understandable and adequate language. It also added that for health related research purposes, local ethics committees should regulate every study, and a written consent form should inform users' participation. As of late 2010, this bill was still under discussion at the Chilean parliament [14], this seems to show the difficulties the system might face when implementing such changes.

Public involvement

The 2003 Health Reform proposed the creation of *Council Care Network Integrators* (CIRA) across the country. These are steering committees that aim to increase health system coordination between different levels of care within private and public systems, and to improve service users' satisfaction and health equalities. Membership includes community participants and members of health services. The CIRAs provide support and advice to each of the health service organizations and propose public policy according to the needs of the community. In December 2009, 35 CIRA were in operation in 606 establishments from the Care Network, including primary care and hospital-based services. Their members represented approximately 3,000 organisations. Moreover, 100% of the 29 *Directorates of Health Services* of the country constituted bodies of public participation; the mechanism provided for a collective approach to the design, presentation and evaluation of public accounts, as well as, generating commitments between the health services, the establishment and the community for the next period. Additionally, all of these health services were initiating participatory budget processes. The thematic priority was the promotion of health, disease prevention, and user satisfaction [13]. Although this policy did not explicitly recognize SDM, it has the potential to support future patients' involvement in healthcare strategies and possibly enhance implementation of SDM.

The Research Agenda 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 $6,800.000 USD. However, none of the funded projects were on shared decisional making (SDM).

According to the draft *Chilean Sanitary Objectives* for 2011-2020, the two major goals on health research are: a) to create a platform which integrates health research conducted across the country; and b) to increase the number of research projects that respond to the new national planning agenda or emerging governmental issues. Although there is no explicit strategy to increase research on SDM, the document includes a brief section on client participation and SDM. This section describes how the *Public Management of Health* has sought advice from the communities through institutions like the *Civil Society, the Consultative Council, the Development Committee, the Local Health Committees*, and tripartite committees, and others. These are all examples of regular participation of representatives from community and social organizations in diagnosing the health situation and assessing the management of network care [13]. However, no information was found regarding translation of SDM into clinical practice.

Shared Decision Making Research in Chile

The development and implementation of SDM research in Chile has been led by *Chilean Schools of Nursing* in collaboration with experienced international researchers from Canada (see Table 1). Nursing recognises the natural ability and capacity of people to take care of themselves including being able to participate actively in their healthcare [15]. To the best of our knowledge, only one research centre, at the *Pontificia Universidad Católica de Chile*, has been working on SDM in Chile.

In 1999, the *University of Ottawa* collaborated with the School of Nursing of the Pontificia Universidad Católica de Chile to implement the first project '*DECIDE*' that was funded by the *Canadian International Development Agency*. The DECIDE project evaluated a program that aimed to support the decision making process of low income women, by training health professionals in SDM and consequently helping women to more effectively use the healthcare system [16]. Findings of this study highlighted that: a) disadvantages women

Table 1. Summary of key SDM Publications resulting from Chilean Research.

Authors	Title	Main findings
Lange et al 2010 [17]	Effect of a tele-care model on self-management and metabolic control among patients with type 2 diabetes in primary care centers in Santiago Chile	Tele-care model was offered to 421 participants and improved compliance to clinic visits, patients' self-efficacy, and HbA1c remained stable in comparison with those who continued receiving usual care
Urrutia et al 2008 [20]	Validation of a Spanish version of the Decisional Conflict Scale	The Spanish version was used with 331 first-year nursing students. The scale had acceptable validity and reliability. Cronbach alpha was 0.80
Campos & Perez 2007 [19]	Self-efficacy and decisional conflict when facing decisions about weight loss in women	Of 101 participants, 77% faced decisional conflict about losing weight and 63% had low self-efficacy with making this decision. A significant association was found between decisional conflict and self-efficacy to lose weight
Bunn et al 2006 [16]	Health preferences and decision making needs of disadvantaged women	Of 554 participants, 75% were currently making a health-related decision. Decisions were primarily about navigation. Those experiencing decisional conflict were more likely to lack information, to be unclear about what was important to them, to feel pressure from others, have inadequate skills or abilities in decision making and be older
Mendoza et al 2006 [21]	Decision making in health and the Ottawa Decision Support Framework	The Framework provides a useful tool for clinical and community practice. Nurses are called to actively participate in the decision-making process
Campos et al 2005 [22]	Academic network to support health decision making	Networking among 6 nursing schools generated a framework for SDM and a model for postgraduate training to be implemented nation-wide
Campos & Marquez 2004 [23]	Decision making of women seeking heatlhcare services for an infant	Of 308 participants, 62% were making a health-related decision. 43% were experiencing decisional conflict. Most salient decisions were related to health system navigation, breastfeeding and health education

were actively involved in making health decisions but required decision support to navigate the system (e.g. whether or when to seek care); b) modifiable factors contributing to making decisions more difficult were similar to non-disadvantages people in other countries; and c) the training program successfully improved nurses knowledge and skills in supporting people making health decisions.

Based on the findings from this initial study, a subsequent project in 2003 funded by the *Canadian Institutes for Health Research* involved the development of a telephone mediated decision support program as an innovative component of a primary health care delivery. The research team was expanded beyond nursing to include other professionals such as physicians, clinical psychologists and engineers. Then in 2006, the *Chilean Fund for the Promotion of Scientific and Technological Development* funded a project to evaluate the implementation of this telephone-based program. More specifically, the telephone mediated self-management and decision support model (ATAS UC) for people with type 2 diabetes enrolled in publicly funded primary care clinics involved interprofessional training of primary care health professionals (e.g. physicians, nurses, dieticians) and showed that patients exposed to the intervention were more likely to stabilise their metabolic control and improve the use of healthcare services [17]. These findings informed the current project funded by the Inter-American Development Bank in 2010 to evaluate the implementation of a mobile-based tele-care follow-up program with diabetics to monitor adherence to their chosen option.

Concurrently, a project was designed to explore decisional conflict among patients with type 2 diabetes and determine implications for cardiovascular health and self-care; funded by the Initiative for *Cardiovascular Health Research in the Developing Countries* (IC Health, India) [18]. Findings revealed that although healthcare professionals agree their role is to support patients making health decisions, half of the patients interviewed did not perceive they were involved in decision making and this was particularly apparent in patients who were less educated. Furthermore, patients experiencing difficutly with decision making felt alone, had inadequate knowledge of their options, and would have liked to have had more discussion with their physician, as well as, printed information.

Two other SDM projects were conducted in the Chilean context as thesis projects for nurses completing their Master's of Science degrees in 2007 and 2008. Campos investigated the self-efficacy and decisional conflict faced by women when losing weight [19]. Bustamante validated a Spanish version of a *Decision Support Analysis Tool for Chronic Disease Management* (DSAT-cdm).

In summary over the last 12 years, there are several research projects that have been conducted primarily in the area of decision support for individuals with diabetes in primary care. These projects have involved needs assessments,

validation of instruments in Spanish, testing of decision support interventions to facilitate shared decision making, and interprofessional training in SDM. Interestingly, no formal training for health professionals in the field of SDM is occurring outside of these projects in either the undergraduate or postgraduate level programs at the Pontificia Universidad Católica de Chile.

Conclusion

SDM is an incipient movement in Chile. Although there is support for SDM in health care reform legislation through statements such as promoting patient participation, much of the shift has been focused on their participation in public policy and not necessarily translated into clinical practice based SDM. However, emerging research indicates the need for better supporting Chileans facing health decisions and effective training and interventions are available. Given the political will to involve and engage patients/public to participate in health related decisions at various levels within the healthcare system, there is an opportunity to push the agenda further by requesting funding to support development, evaluation, and wider-scale implementation of programs to facilitate SDM across healthcare services. These initiatives could evolve from the current infrastructure focused on SDM in diabetes management. Finally, there is a need to more systematically assess the decision making needs of the Chilean population and determine the extent to which their needs could be supported by current resources or require development of new interventions.

Acknowledgement

The authors would like to thank Professor Ilta Lange and Professor Mila Urrutia for their valuable contribution and the review of this article.

References

[1] International Monetary Fund I. Report for selected countries and continents: Latin America and the Caribbean GDP ppp in 2010. 2011 [cited 2011 January]; Available from: http://www.imf.org/external/pubs/ft/weo/2010/02/weodata/index.aspx].

[2] Health Chilean Minister. Sistematización de estudios de red asistencial: visión nacional. In: DINRED., editor. Santiago: Ministerio de Salud; 1999.

[3] Albala C, Vio F. Epidemiological transition in Latin America: The case of Chile. Public Health 1995;109:431–42.

[4] Infante A, De la Mata I, Lopez-Acuna D. Reforma de los sistemas de salud en América Latina y el Caribe: Situación y tendencias. Revista Panamericana de la Salud 2000;8:13–20.

[5] Arteaga O, Thollaug S, Nogueira AC, Darras C. Informacion para la equidad en salud en Chile. Pan Am J P Health 2002;11(5/6):374–85.

[6] Ministerio de Salud Chile M. Encuesta Nacional de Salid Chile, ENS 2009-2010. 2010.

[7] Oyarzo C. La descentralización financiera en Chile en la década de los noventa. Revista Panamericana de la Salud 2000;8:72–82.

[8] Arteaga O, Astorga I, Pinto AM. Inequalities in public Health care provision in Chile. Cad Saúde Pública. Rio de Janeiro 2002;18(4):1053–66.

[9] Vega J, Hollstein RD, Delgado I, Perez J, Carrasco S, Marshall G, et al. Socioeconomic Health Inequities in an Intermediate-development nation: Chile, 1985-1996. In: Evans T, Whitehead MDFBA, Wirth M, editors. Challenging Health Inequalities: From Ethics to Action. New York: Oxford University Press; 2001. p. 122–37.

[10] Health Chilean Minister. Serie CASEN 2003. Pobreza, distribucion del ingreso e impacto distributivo del gasto social. Gobierno de Chile. 2004.[cited 2009 August]; Available from: http://www.risolidaria.tdata.cl/Portada/Dirseccion/Home_tercer_sector.asp?dir=Documentos_de_Analisis_TS&id=3893].

[11] Drago M. La reforma al sistema de salud chileno desde la perspectiva de los derechos humanos. 2006.

[12] Panamerican Health Organization PHO. Informacion para la equidad en salud en Chile. Oficina Sanitaria Panamericana, Oficina Regional de la Organizacion Mundial de la Salud Representación en Chile. 2001.[cited 2009 July]; Available from: http://www.bcn.cl/carpeta_temas/temas_portada.2005-10-27.7644862447/documentos_pdf.2005-10-28.2320771530].

[13] Health CMo. Objetivos estrategicos de la decada 2011-2020. Primer borrador para consulta publica. 2010.[cited 2010 November]; Available from: www.minsal.cl].

[14] Mensaje de S.E. la Presidenta de la República con el que inicia un proyecto de ley que regula los derechos y deberes que las personas tienen en relación con acciones vinculadas a su atención en salud, (2006).

[15] Orem DE. Nursing: concepts of practice. St. Louis: Mosby-Year Book Inc; 1991.

[16] Bunn H, Lange I, Urrutia M, Campos MC, Campos S, Jaimovich S, et al. Health preferences and decision-making needs of disadvantaged women. Journal of Advanced Nursing 2006;56(3):247–60.

[17] Lange I, Campos S, Urrutia M, Bustamante C, Alcayaga C, Tellez A, et al. Efecto de un modelo de apoyo telefónico en el auto-manejo y control metabólico de la Diabetes tipo 2, en un Centro de Atención Primaria, Santiago, Chile. Revista Medica de Chile 2010;138:729–37.

[18] Campos S, Stacey D, Urrutia M, Jaimovich S, Perez J. Decision making needs of Chilean patients with type 2 diabetes with implications for self care management: a descriptive study. Chronic Disease:Prevention & Management; Canada2007.

[19] Campos S, Perez JC. Self-eficacy and decisional conflict facing the diminution of corporal weight in women. Revista Chilena de Nutricion 2007;34(3):213–8.

[20] Urrutia M, Campos S, O'Connor A. Validation of a Spanish version of the Decisional Conflict Scale. Revista Medica de Chile 2008;136:1439–47.

[21] Mendoza PS, Jofre AV, Valenzuela SS. Decision-making in health and the Ottawa decision-support framework. Investigacion y educacion en enfermeria 2006;24(1):86–92.

[22] Campos C, Urrutia M, Campos S, Campos MS. Academic network related to health decision making. Revista Iberoamericana de Investigacion Ciencia y Enfermeria 2005;11(1):25–35.

[23] Campos S, Marquez F. Decision making process of women attebding infant health care. Revista Horizonte de Enfermeria 2004;15:53–61.