Shared Decision Making in Brazil. Concrete Efforts to Empowering Patient’s Voice

Partizipative Entscheidungsfindung in Brasilien: konkrete Anstrengungen zur Stärkung der Stimme der Patienten

Mirhelen Mendes de Abreu 1,*, Joao Pedro Simao de Mello 2, Lilah Ferreira F. Ribeiro 2, Luiza Andrade Mussi 2, Mariana Luiza L. Borges 2, Mauricio Petroli 2, Nycholas da Costa Tavares 2, Rafael da Cunha Cancela 2, Sabrina Fausto de Lima 2

1 Division of Rheumatology, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil
2 Undergraduate Medical Student, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil

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ABSTRACT
Patient involvement in healthcare decisions has grown in Brazil at three different levels: 1) the macro level, which includes the patient actively influencing legislation and regulation of medical care as well as political changes in the process of care itself; 2) the meso level, which includes institutions that aim to improve information, empowerment and counseling to patients, and 3) the micro level, which focuses on the actual decision-making process that takes place within patient-physician encounter. In Brazil, the macro and meso levels are stronger than the micro one. In this paper, the practical efforts to engage patients in the center of their own care are presented. In order to do that, an overview on the National Humanization Policy and the Brazilian patient’s movement is provided.

ZUSAMMENFASSUNG
Die Beteiligung von Patienten an gesundheitsbezogenen Entscheidungen hat in Brasilien auf drei verschiedenen Ebenen zugenommen: 1) auf der Makroebene (dazu gehört der Patient, der aktiv Einfluss auf die Gesetzgebung und die Steuerung der medizinischen Versorgung sowie auf politische Veränderungen im Versorgungsprozess selbst nimmt); 2) auf der Mesoebene (dazu gehören Einrichtungen, die eine Verbesserung der Information, des Empowerments und der Beratung von Patienten anstreben) und 3) auf der Mikroebene, die auf den eigentlichen Entscheidungsfindungsprozess fokussiert, der im Rahmen des Arzt-Patient-Kontakts stattfindet. In Brasilien haben die Makro- und die Mesoebene ein stärkeres Gewicht als die Mikroebene. In diesem Beitrag berichten wir über die praktischen Bemühungen, Patienten stärker in den Mittelpunkt ihrer medizinischen Versorgung zu rücken. Dazu geben wir hier einen Überblick über die nationale Humanisierungspolitik und die Patientenbewegung in Brasilien.

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SDM at the macro level

In Brazil, there have been practical efforts to establish the National Humanization Policy (Política Nacional de Humanização, PNH), which is a Public Health policy based on two main principles. The first one is the principle of inseparability of clinical practice and politics, which implies the inseparability of medical care and
health management. The second one is the principle of transversality, understood as growing and open communication among the stakeholders involved in the healthcare [1].

The directives of NHP are its general guidelines, i.e., practices that intend to include all involved stakeholders, such as patients (called as users of the healthcare system), health workers and healthcare service managers. Such practices are: expanding clinical services, co-managing services, and evaluating the work, reception and the protection of user’s rights, among others.

Humanization, as outlined in the NHP, is put into effect in health practices by the actions aforementioned: i.e., the different approaches used by individuals in their routine services. It is directed towards ordinary men and women who make up the SUS1, through their experiences with the workers and users who live and perform day-to-day healthcare services.

Therefore, the principle of working in health services focuses on the concept of humanness and humanism, and its goal is to enable a better understanding of how to establish a health service as well as a better understanding of the process of working in healthcare. Regarding the PNH, this principle is implemented by analyzing services, observing workers and users of those services, and the different ways of being and acting in SUS.

This process has been applied through a number of strategies: a) invite and include all those who campaign in the SUS to discuss the service (workers, managers and users/ patients); b) consider variables that constitute the entire service and the whole process of the workplace in order to analyze the working process, c) review the organizational structure in order to compose a working team centered on the patient.

“Institutional support, in the sense attributed to it by the National Human Policy, establishes a dynamic relationship between the institutional supporter and the team supported: it is neither an active nor and active work, but rather a collection of actions, opinions, plans and protocols or standards for the benefit of the team. The participation of the user in this context is still rather incipient. The function of the institutional supporter is to contribute to the management and organization of the working processes, in the construction of collective spaces where groups analyze, define tasks and elaborate intervention projects” [2].

In order to implement the humanization principle, some actions have been applied, such as conversation circles, common spaces that include different stakeholders, among others. However, it is not only that action that is performed but how incisively and distinctly it is performed that defines the intensity and quality of the institutional support. This proposed path greatly opposes and differs from the strategies based on prescribing rules for the implementation of a service, which is incompatible with the very concept of how PNH works.

SDM at the meso and micro level

Many efforts have been developed in order to promote instruments to support patient information. Specialty societies have promoted educational materials to guide and provide educational tools in various diseases. Additionally, groups of patients have been institutionally articulated, ensuring that common decisions on health policies have the participation of both the patients and the society. In general, groups of patients are classified as non profit organizations, regulated by federal guidelines.

Patient Associations

Groups of patients aim to empower and counsel patients, family and caregivers in an interactive environment. Their actions include education, social mobilization on the importance of early prevention, diagnosis, treatment and rehabilitation of rheumatic diseases through education in health, in Brazil.

In addition, many groups of patients have legal roles, which usually means providing legal council to patients and advise them in matters with the Public Policy so that they can be guaranteed access to the best treatments, new technologies and health education.

Patient Information Support Centers

Information instruments for patients have been developed by specialty societies, by non-profit organizations and by SUS itself. These instruments have been developed both to provide information on the diseases and to guide the patient within the public and private healthcare system.

Final considerations

Health care has become increasingly patient-centred in Brazil, especially after the establishment of the Unique Health System (SUS) in 1989. The creation of this national healthcare system was a response to social participation and population demands of access to health care. Patient participation is a result of a national political movement that involved different informal popular representatives, physicians, other health professionals, hospital managers and politicians. In this context, patient participation is stronger on meso and macro political decisions in health, and following this trend, individual shared decision making is an emerging practice. Some efforts are being developed to improve this theme in research and practical fields [3].

Conflict of Interest

The authors have no potential conflicts of interest.

References


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1 A Brief Overview of SUS

SUS (Sistema Unico de Saúde) is the Unified Health System in Brazil. SUS is a set of actions and services of health provided by municipal, state and federal spheres supported by public authorities and with a complement by private initiative (Federal Law 8.080/90). SUS aims to assist the population based on model of promoting, protecting and rehabilitating health. The efforts to achieve these goals - including their process, framework and methods – have been designed to efficiently allocate the resources of the country. The principles of SUS are: universality (healthcare for all citizens); equity (level of hierarchy according to complexity of the health care needed); integrity (bio-psycho-social perspective for health assistance); the principles and fundamentals of SUS are the same in all national territory under three government autonomous spheres: federal, state and municipal.
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