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ORIGINAL ARTICLE

SHARED DECISION MAKING IN HEALTH: REFLECTIONS ON POLITICAL AND REGULATORY INCORPORATION IN BRAZIL

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ABSTRACT

Objective: to analyze the incorporation of shared decision making in Brazilian public health policies and regulations that guide patients’ care, considering their interfaces with patient-centered care and patients’ rights. **Development:** reflection article that seeks to identify, in the two main national regulations that comprehensively address patients’ care, the Health Users’ Charter and the National Humanization Policy (NHP), the inclusion of the SDM (Shared Decision Making) model as an imperative ethical element during clinical care. Interactions between patients and health professionals are considered asymmetrical. To promote more symmetrical clinical encounters and health-related decisions that consider the patients’ needs and desires and drive the quality of care, global guidelines recommend the implementation of patient-centered care through shared decision making. **Conclusion:** The inclusion of the patients as active agents in the therapeutic decision making process in Brazil is not yet a reality. Shared decision making is a gap in national regulations and in the documents defining public health policies that comprehensively guide the clinical encounter.

Keywords: Shared Decision Making. Patient Rights. Patient-Centered Care.

INTRODUCTION

The introduction of the term Shared Decision Making (SDM) in the health field is historically attributed to the President's Commission of the United States(1), which published the report “Making Health Care Decisions”(1) in 1982. The document examined the relationships and communications between patients and health professionals in a broader context(1) and recommended a change in the relationship model in health care, consolidating SDM as a reference to be implemented during clinical encounters(1,2).

The dissemination of SDM, despite having emerged in the 1980s, is concomitant with the implementation of the biopsychosocial model of health approach and the Patient-Centered Care (PCC) framework, which have spread more widely since the early 2000s(3). There is consensus in global health systems about the importance of implementing SDM in clinical practice, as it is considered an effective model for respecting patients’ autonomy, enabling informed decisions about their health(1,3). It is emphasized that SDM is considered an ethical imperative for all professionals involved in care(2).

SDM emerged from studies in research centers and has reached health regulation in several countries. In the United States of America (USA), the Agency for Healthcare Research and Quality (AHRQ) recommends the use of evidence in making informed health decisions(4). In 2007, the State of Washington passed legislation that encouraged the use of SDM in health care and began a project to evaluate the adoption of the model(4). “In England, the debate on SDM — aimed at continuous improvement in the quality of health services — began in 2006. That same year, the National Institute for Health and Care Excellence (NICE) published a guide recommending that all health professionals, at all levels of care, incorporate SDM(5).

In Latin America, Chile incorporated the term SDM into official documents in 2021. The country proposed a reformulation of the health care model, adopting the PCC and SDM(6). To this end, it emphasized the need for professional training and the encouragement of the use of health decision-making technologies (6).

In 2016, the World Health Organization

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(WHO) recommended the structuring of integrated, patient-centered health services, explicitly calling for health systems to be designed for patients and not for diseases(7). As a strategy, it emphasized the importance of collaborative care planning between patients and professionals, through the incorporation of SDM(7).

In this context, considering the importance that SDM has acquired over time in the health systems of several countries, the guiding question of this work was how is SDM integrated into Brazilian public health policies? Thus, this article aims to analyze the incorporation of SDM into Brazilian public health policies and regulations that guide patient care, considering its interfaces with the PCC and patients' rights.

DEVELOPMENT

This is a reflective article that investigates how the two main national regulations on patient care — the Health Users' Charter(8) and the National Humanization Policy (NHP)(9) — incorporate the SDM model as an ethical imperative in clinical care, enabling the realization of Patient Rights (PR).

The documents were chosen because they are the only national regulations applicable to all patients, and concern the guidance of the professional's behavior and their relationship with the patients. This reflection starts from the concept of SDM, of global relevance in the improvement of health systems, then addresses the intersections between SDM and the PCC, then demonstrates the articulation between SDM to guarantee PR. Finally, it discusses the incorporation of SDM in the proposed documents of the Brazilian health system, and the realization of PR through SDM in the Brazilian context.

Concept and importance of Shared Decision Making

Interactions between patients and healthcare professionals are notably described as asymmetrical and characterized by the mitigation of the importance of patients' knowledge and their unique experience of illness(4). In this sense, SDM is considered an antidote to paternalism, as it is part of the mutuality model, which advocates a partnership between healthcare professionals and patients in decision-making(10).

The President's Commission based SDM on respect and mutual participation of patients and healthcare professionals in decisions about care. It emphasized the importance of an informed decision and the promotion of decision-making that considers the extent to which the patient wishes to participate in the process(1).

SDM is currently defined as a collaboration between the patients and the healthcare professionals to make decisions about diagnostic tests, choice of treatment, care or monitoring, in the manner that is preferable for the patients(11). This process includes evidence-based health information about options, benefits, and harms, as well as support for the patients to explore their own values and preferences(11).

Globally, SDM is referenced as the main method that ensures patients participate in decisions, and that considers their willingness to be involved in decisions made in their health care. The use of SDM in clinical encounters is associated with improved quality of care, reflected in continuous gains in patients' knowledge, understanding, satisfaction, and confidence in their own choices(2). In the same sense, behavioral aspects such as adherence to treatment and adoption of beneficial behaviors are correlated with the greater diffusion of SDM in the most diverse types of specialties and levels of health(2).

SDM and Patient-Centered Care

Patient-Centered Care is defined as health care that establishes a partnership between professionals, patients, and their families to ensure that decisions respect the wishes, needs, and preferences of patients and that patients have the necessary education and support to make decisions and participate in their own care(12).

In the early 1970s, PCC was included in discussions about health policies in countries. In 1978, the World Health Organization (WHO) Declaration of Alma Ata declared that people had the right and duty to participate individually and collectively in the planning and implementation of their health care, emphasizing the importance of including patients in decisions about their health(13). In 2016, the WHO ratified the structuring of health services in an integrated and person-centered manner(7).

In the 1990s, the Picker Institute, together with the Harvard School of Medicine, defined the dimensions of PCC from the perspective of patients. Later, the US Institute of Medicine reinforced this framework in the Crossing the Quality Chasm report (2001), which proposed six objectives to transform the North American health system — including the PCC as one of the pillars of quality and patient safety(14).

SDM is evaluated as a support for the implementation of the PCC, being an ethical duty of health professionals directly involved in care(15). However, many professionals, organizations and health systems have not yet understood that the PCC is comprehensive and incorporates actions for planning and implementing a quality health system(12).

Links between SDM and Patient Rights

Patient Rights is a new branch of law that has emerged from the cultural, political, legal and ethical changes that have occurred in healthcare over the last few years and which began at the end of the 20th century. In fact, the systematization of patient rights as a legal and interdisciplinary field results from the recognition of the centrality of patients in their own care, the importance of their participation and the obligation of States to adopt laws and public policies that protect them due to their greater vulnerability. Thus, it is noted that Patient Rights are associated with this movement in healthcare that establishes a new paradigm, replacing the patient as the object of care with the patient as the subject and agent of his own care. This new paradigm unfolds into several approaches, such as the PCC, Patient Participation and SDM, which consist of ethical foundations of Patient Rights. At the same time, in a dialogical interface, patients' rights, such as the right to information and the right to participate in decision-making, constitute tools for the implementation of the PCC, Patient Participation and SDM. Thus, this article assumes that SDM offers theoretical and practical foundations for Patient Rights, providing concepts and procedures that support the implementation of these rights. In this sense, it is emphasized that establishing that patients have the right to participate in decision-making in the form of public policies is fundamental, but insufficient for this to be shared(5). From the perspective of Patient Rights, it is argued that such rights are tools that contribute to the adoption of SDM in clinical practice, guided by the recognition of the patient as a moral agent who makes decisions about his or her own life and health.

SDM is also an ethical approach that expresses an option for promoting the patients' personal autonomy, their participation in decisions that affect them and respect for their centrality in health care. In this way, SDM connects with the recognition that patient participation in decision-making is an imperative ethical command, since disregarding it translates into their objectification and dehumanization. In this sense, the motto “Nothing about us, without us” — originated in the disability rights people movement — was incorporated into health care as a fundamental ethical principle, reinforcing the right of patients to participate in decisions that concern them, whether in public policy, hospital management or clinical care. Although this motto was introduced into health by patient rights movements, patient participation in decision-making is important for all actors involved, that is, the health team also has much to gain(16). In the agenda of the National Health Service of the United Kingdom, this motto was adopted as the foundation of SDM(17).

In this way, SDM ensures the patient's right to participate as one, being considered “the rights of rights”, as it consists of the basic right of all people to participate in decisions that affect their lives(18). In effect, the patient holds the right to be involved in planning and decision-making about health and care(5) and, ultimately, to determine them(19). This right involves respecting the extent of his/her will to participate or not in decision-making, as an expression of the patient's self-determination(15). Therefore, the patient's right to participate in decision-making encompasses his/her role as a central actor in SDM, which implies revisiting his/her knowledge, concerns and perspective, with a view to seeking an agreement on the course of treatment(20). The realization of this right implies the patients being informed and supported, receiving information about diagnostic tests, treatment options and their benefits and risks(5). Furthermore, the exercise of the right to participation presupposes certain attitudes of professionals, such as considering the patient as a unique person; sharing power; valuing the patient's experiential knowledge; active listening and effective communication, as well as providing physical and emotional support.

SDM also guarantees the patients' right to information, since it presupposes the sharing of information by the health professional, with the description of the probable benefits and potential risks of the treatment options(21). Without accessible and quality information, the patient is not able to understand the main points of SDM, therefore, it is necessary for the professional to provide information adjusted to the patient involved so that he/she can effectively participate in the decision-making process(18).

Although the decision in SDM is collaborative, there is no doubt(17) that the patient is the final decision-maker. If there is no consensus, he/she has the right to accept or reject the proposals of the health team.

SDM is also intertwined with one of the principles of Patient Rights, the principle of promoting personal autonomy(10), as it has the power to promote it in the clinical encounter(17). Respect for autonomy, in a traditional view, consists of the command of non-interference in the individuals' private space, entailing for the State and society an obligation not to prevent people from making choices about life plans according to their will and preferences. Currently, this traditional view has been supplanted by the principle of promoting personal autonomy, that is, there is also a command in the sense that measures must be adopted to provide means of exercising personal choices, not just respecting them(22). This is due to the understanding that autonomy is not mere self-government or self-legislation, since decisions about one's own life are made in relational contexts, which positively or negatively interfere both in the selection of choices and in their execution. Therefore, if the external environment directly impacts autonomy, which implies conceiving choices and executing them, this environment can promote it, that is, support the individual in identifying their will and preferences and acting accordingly. On the other hand, oppressive means have the power to hinder self-knowledge and the perception of what the individual wants for themselves, as well as to act according to their life plan. Therefore, SDM helps the patients to be involved in the decision-making process, exercising their right to participate and the right to information. It is emphasized that the patient is the ultimate decision-maker, in accordance with his right to consent or not, with the courses of action that emerge from the dialogue established within the SDM. In this sense, SDM ensures the rights of patients to be informed and to be involved in decisions(2). At the same time, patient rights are a tool that promotes the implementation of SDM, being seen, from the perspective of the language of rights, as an ethical imperative that ensures them, which makes it a command for health services and systems.

Shared Decision Making and Guiding Documents on Clinical Relationships in Brazil

In Brazil, public health care provided within the Unified Health System (SUS) has two main references in the ethical and legal regulation of clinical relationships: the Health Users' Charter(8) and the National Humanization Policy (NHP)(9). The application of these references in the SUS, as well as in the private health system, is not mandatory, as neither are legal in nature, becoming merely recommendations for health services(10).

The Health Users' Charter originated in Ordinance number 1,820, approved by the National Health Council and published in 2009. The document emerged after the beginning of global discussions on PCC and SDM, and, despite this, there is no mention in the foundations of the document of the centrality of the patient in health care. The fourth principle of the Charter — among the six presented — addresses the right to care that respects the patient, his values and rights(8). Although it is in line with the principles of the PCC and, eventually, with SDM, it does not place the patients at the center of care nor recognize their role as decision-makers. In addition to the concrete absence of the PCC framework, there are multiple topics covered that refer not only to the patient, but to the duties of professionals and health institutions, corroborating the failure to provide the due centrality of the patient, increasing the gap in adequate planning for the patient.

It is worth noting that the Charter does not mention the patients' participation in the decision-making process related to their care, therefore, the patients' right to participate in decisions about their care is not contemplated. Thus, the Charter disregards the importance of experiential knowledge and the role of the patient as a protagonist in the clinical encounter, limiting the incorporation of his needs, will and preferences during the decision-making process, limiting his role solely to consent regarding the procedures indicated by the health professionals.

The right to information, presented in Article 4 of the Charter, includes knowledge about different therapeutic possibilities based on scientific evidence, as in SDM. However, the right restricts the patient's role to choosing treatment alternatives or refusing them. There is no reference to the information provided by the professionals in the context of a participatory process.

The Charter establishes the patient's responsibility to follow the therapeutic plan proposed by the health professional, after understanding and accepting it. Thus, it is clear that there is no provision for the need for a process of reflection and joint decision-making between the patient and the professional, disregarding the co-participation and partnership advocated in SDM in all decisions that impact the patient's life (3).

The National Humanization Policy (NHP), launched in 2003 by the Ministry of Health (MH), aimed, among other objectives, at incorporating new technologies, knowledge and practices into public health policy at a national level(9). It proposed changes to the management and health care model within the SUS, with the valorization of the autonomy and protagonism of those involved in the health system, including patients(9). This proposal for organizing the SUS is, like the aforementioned Charter, subsequent to the PCC and SDM model and does not include the incorporation of PCC and SDM. Both, patient and professional, are treated as 'subjects' on an equal footing, ignoring the historical asymmetry and vulnerability of the patient. This levels distinct needs and disregards the differentiated attribution of roles and responsibilities, whose sole purpose should be the well-being of the patient. The proposed policy emphasizes the importance of management and the health "worker", to the detriment of effective methods to promote the PCC and implement SDM. Among the principles of the NHP, protagonism is one of the basic components. However, it does not define to whom this precept applies, encompassing patients and professionals at the same level, failing to recognize the central role of the patient in care, contrary to what is indicated by the SDM. It presents the co-responsibility indicated in the SDM; however, this applies to management and care processes in a mixed manner, correlated to collectives (all those involved), not conferring specificity to the context of individual health care and clinical decisions.

The PNH focuses on the planning, organization and management of health systems in the country. In the item of implementation in Brazil, it guides institutions, management and financing and, lastly, the axis of health care, focusing on work processes and without addressing clinical decisions.

The PNH mainly describes actions aimed at "health workers", with regard to the patient (user) it focuses on ensuring social participation, individual or collective, such as the guarantee of "User Rights" and participation in collegiate management. The NHP does not define any strategy to support patients in playing an active role in health care, especially regarding clinical decisions.

Thus, the Charter and the NHP do not provide for the search for an agreement between patients and health professionals regarding the course of treatment. This is confirmed by the absence of the term SDM and its definition, demonstrating that this concept has not yet been incorporated into national health policies. This reality leads to difficulties in implementing the change from the paternalistic model to the mutuality model, which involves a partnership between the professionals and the patients. The asymmetry of power between the health professionals and the patients is perpetuated, which should be mitigated through the adoption of SDM in the clinical encounter as the main characteristic of a PCC.

The normative incorporation of SDM in the world and in Brazil

The process of normative incorporation of

SDM is underway in some countries. For the purposes of this study, the normative incorporation of the provision of SDM in law or in an infra-legal act, such as a decree, ordinance or resolution, is considered. Since SDM is an approach that promotes essential patient rights, it is understood that it must be contained in a law that provides for its general aspects or that there is a legal provision for the patients' right to participate in decision-making regarding their health. For example, in the Netherlands, due to the movement initiated by the National Patients' Federation, the verb "to decide together" began to be adopted, expressed in the understanding that SDM encompasses "dialogue about choices, dialogue about options, dialogue about preferences and dialogue about the decision". In January 2020, SDM is expressly mentioned as a prerequisite during meetings between physicians and patients in the Dutch law on the "Medical Treatment Agreement". Healthcare professionals have a legal duty to introduce the option of not adopting any treatment and to explore patient preferences(23). In the US, the State of Vermont also includes SDM in its legislation, and other states, Connecticut, Massachusetts, Maine, Minnesota, New Hampshire and Oklahoma, have considered adopting a legislative approach to promote SDM(4). From the perspective of healthcare professionals, an example is the General Medical Council of the United Kingdom, which, when updating its guidelines on informed consent, explicitly linked it to SDM, highlighting the fundamental relationship between the two for clinical practice(5). Physicians were advised to try to identify what matters to patients, and should share relevant information about the benefits and harms of proposed treatments or management options and reasonable alternatives, including the option of not treating(5).

In Brazil, there is no legal provision for SDM, not even a national PR law. Legislation on PR would establish essential rights to ensure quality of care and respect for the dignity and integrity of the patients in healthcare. These rights are understood globally as a minimum ethic, consisting of one of the most important components of human and ethical care(24), prescribing to health professionals how they should act in relation to patients.

National PR legislation began to be adopted in the 1990s, with Finland being a pioneer. Around the world, there are countries that have already addressed patient rights, such as: Ecuador, Argentina, Chile, United Kingdom, Hungary, Belgium, Spain, Estonia, Lithuania, the Netherlands, Slovakia, Finland, Denmark, South Africa, Kenya, Uganda, Israel(10). Global evidence shows that the relationship between health professionals and patients is asymmetrical(3), both in relation to the power and information of professionals, and prone to abuse. And although some isolated national actions intend to promote patient autonomy(25), the law is essential to create a culture of respect for the patients.

It is worth noting that Bill 2242/22: "Patient's Rights Statute" provides for patient's rights and is aimed at: healthcare professionals; those responsible for public or private healthcare services; and private legal entities that operate healthcare plans. The aforementioned Bill provides in art. 11 that: "The patient has the right to be actively involved in his/her healthcare, participating in the decision-making process regarding his/her healthcare and therapeutic plan". Thus, it is clear that SDM is provided for in the aforementioned Bill, as it guarantees that the patient has the right to be involved in his/her healthcare and participate in the decision-making process. The Bill was approved by the Chamber of Deputies and is currently in the Federal Senate(26).

FINAL CONSIDERATIONS

Despite the broad global consensus on the importance of PCC and SDM in healthcare, these concepts have not been formally incorporated in Brazil, negatively affecting practices. Patient participation as a decision-maker in their therapeutic plan is still not an ethical and legal principle guiding healthcare services in the country.

This dissonance between what is recommended and adopted in various healthcare systems and the Brazilian reality demands reflection and decision-making, especially on the part of SUS managers.

Therefore, there is a pressing challenge regarding the recognition and guarantee of the centrality of the patient and the established benefits of SDM for clinical results and

sustainability of healthcare systems. Thus, it is urgent to review policies in line with healthcare based on PCC and SDM.

TOMADA DE DECISÃO COMPARTILHADA EM SAÚDE: REFLEXÕES SOBRE INCORPORAÇÃO POLÍTICA E NORMATIVA NO BRASIL

RESUMO

Objetivo: analisar a incorporação da tomada de decisão compartilhada nas normativas e políticas públicas de saúde brasileiras que balizam o cuidado do paciente, considerando suas interfaces com o cuidado centrado no paciente e os direitos dos pacientes. **Desenvolvimento:** artigo de reflexão que busca identificar, nas duas principais normativas nacionais que abordam de maneira abrangente o cuidado ao paciente, a Carta dos Usuários da Saúde e a Política Nacional de Humanização (PNH), a inclusão do modelo da TDC como elemento imperativo ético durante o atendimento clínico. As interações entre pacientes e profissionais de saúde são consideradas assimétricas. Para promover encontros clínicos mais simétricos e decisões relacionadas à saúde que considerem as necessidades e os desejos do paciente e impulsionam a qualidade do cuidado, as diretrizes mundiais recomendam a implementação do cuidado centrado no paciente, por meio da tomada de decisão compartilhada. **Conclusão**: a inclusão do paciente como agente ativo no processo decisório terapêutico no Brasil ainda não é uma realidade. A tomada de decisão compartilhada é uma lacuna nas normativas nacionais e nos documentos definidores de políticas públicas de saúde que, de maneira abrangente, norteiam o encontro clínico.

Palavras-chave: Tomada de Decisão Compartilhada. Direitos do paciente. Cuidado centrado no paciente.

TOMA DE DECISIÓN COMPARTIDA EN SALUD: REFLEXIONES SOBRE INCORPORACIÓN POLÍTICA Y NORMATIVA EN BRASIL

RESUMEN

Objetivo: analizar la incorporación de la toma de decisiones compartida en las normativas y políticas públicas de salud brasileñas que fundamentan el cuidado del paciente, considerando sus interfaces con el cuidado centrado en el paciente y los derechos de los pacientes. **Desarrollo**: artículo de reflexión que busca identificar, en las dos principales normativas nacionales que tratan de manera integral la atención al paciente, la Carta de los Usuarios de la Salud y la Política Nacional de Humanización (PNH), la inclusión del modelo de la TDC como un factor ético imperativo en la atención clínica. Las interacciones entre pacientes y profesionales de la salud son consideradas asimétricas. Para fomentar encuentros clínicos más simétricos y decisiones relacionadas con la salud que tengan en cuenta las necesidades y los deseos del paciente e impulsen la calidad de la atención, las directrices mundiales recomiendan la implementación de la atención centrada en el paciente, a través de la toma de decisiones compartida. **Conclusión**: la inclusión del paciente como agente activo en el proceso de toma de decisiones terapéuticas en Brasil aún no es una realidad. La toma de decisiones compartida es una laguna en las normativas nacionales y en los documentos definidores de políticas públicas de salud que, de manera integral, guían el encuentro clínico.

Palabras clave: Toma de Decisiones Compartida. Derechos del paciente. Atención centrada en el paciente.

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