






## NURSES AND PATIENT ADVOCACY: A THEORETICAL REFLECTION

### O ENFERMEIRO E O EXERCÍCIO DA ADVOCACIA DO PACIENTE: REFLEXÃO TEÓRICA

### EL ENFERMERO Y EL EJERCICIO DE ABOGACÍA DEL PACIENTE: REFLEXIÓN TEÓRICA

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#### ABSTRACT

This study's objective was to present a reflection upon the role of nurses as patient advocates, considering the current context of health services in Brazil. The role of a patient advocate has been added to the practice of nurses in order to promote and defend the interests and wellbeing of patients, ensuring patients are aware of their rights and have access to information to improve their health. A discussion regarding the difficulties and ethical challenges nurses face, especially when advocating for patients, should be intrinsic to daily health practice and especially during academic training. The conclusion is that the nursing field has a long way forward in terms of patient advocacy, so that in the future, this activity will be based on daily practice.

**Keywords:** Nursing; Health Advocacy; Ethics, Nursing; Education, Nursing.

#### RESUMO

*O presente estudo buscou tecer reflexão acerca da atuação do enfermeiro no exercício da advocacia ao paciente frente à atual conjuntura de serviços de saúde no Brasil. Para o profissional de Enfermagem a advocacia em saúde ainda está sendo acrescida como função, a fim de promover e defender os interesses e o bem-estar do paciente, assegurando que ele detenha o conhecimento dos seus direitos e acesso às informações, melhorando a sua saúde. Discutir sobre as dificuldades e desafios éticos da profissão do enfermeiro, sobretudo a atividade de advogar pelo usuário, deveria ser intrínseco às práticas diárias de saúde realizadas, principalmente durante a formação acadêmica. É possível concluir que a Enfermagem tem um caminho a percorrer no que concerne à advocacia do paciente, para que futuramente possa alicerçar essa atividade à sua prática diária.*

**Palavras-chave:** Enfermagem; Advocacia em Saúde; Ética em Enfermagem; Educação em Enfermagem.

#### RESUMEN

*El estudio ha buscado hilar reflexiones sobre la actuación del enfermero que ejerce la abogacía del paciente ante la actual coyuntura de los servicios de salud de Brasil. Para el profesional de enfermería la abogacía en salud todavía se está incrementando como función con miras a promover y defender los intereses y el bienestar del paciente, garantizándole el conocimiento de sus derechos y acceso a la información, mejorando su salud. Discutir sobre las dificultades y retos éticos de la profesión del enfermero y, sobre todo, el ejercicio de abogacía del paciente, debería ser algo intrínseco a las prácticas diarias de salud, principalmente durante la formación académica. Se concluye que Enfermería tiene por delante mucho para recorrer en lo que se refiere a la abogacía del paciente para que, en el futuro, pueda consolidarse en la práctica diaria.*

**Palabras clave:** Enfermería; Defensa de la Salud; Ética en Enfermería; Educación en Enfermería.

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## INTRODUCTION

The initial understanding of what is called “patient advocacy” goes back to the not-so-distant past and comprises different aspects. The first aspect is directly related to the emergence of human rights after Nazism and the barbarities of totalitarian regimes in the 20th century. These two extreme situations outlined a normative system of protection, which, in 1948, was proclaimed by the United Nations (UN) as the Universal Declaration of Human Rights. This declaration adopts common parameters for all peoples and nations, grounding and recognizing universal and indivisible rights that include from labor rights to those of priority and vulnerable social groups or groups that suffer discrimination. In this sense, before the existence of the UN, countries assumed the ethical and moral commitment to ensure their populations possessed the rights contained in the treaty. In the Brazilian context, the current economic crisis is a factor that may threaten human rights, because budgeted funds previously intended to be transferred to social policies has decreased, harming the most vulnerable citizens. Poverty, hunger, poor education, unemployment, poor and precarious working conditions, lack of basic sanitation, and inadequate housing conditions reveal social inequality and, most important, disrespect for human rights.<sup>1</sup>

The context of health is part of this impasse, as it includes the broadest understanding of the right to health; right to life, health, and wellbeing. According to the Brazilian Constitution of 1988, health is a fundamental right ensured through a public health policy, the *Sistema Único de Saúde* (SUS). This system, which is linked to structural aspects of Brazilian society (such as social inequality, social conflicts, the non-implementation of redistributive and inclusive public policies, among others), is not able to ensure social rights fully. Considering health as a right of all and fully ensuring such a right is not a simple task. Its interface has two dimensions: advocacy and care delivery. In this sense, health being a fundamental human right is the basis for the exercise of the remaining rights. It is up to the Democratic Rule of Law to adopt measures that facilitate individuals’ access to the right to health, respecting, protecting, and fulfilling the protection of Human Rights.<sup>12</sup>

Health workers are at the top of the Brazilian system. They experience on a daily basis the increasing infeasibility of supplying health services to people, and are unable to implement the principles of SUS effectively, having to face the dilemma of reconciling ethical with operational principles. As a result, the delivery of care has not met the principles of humanized care and excellence, even though health workers provide care to patients with the consideration that every patient has the right to quality care delivery, personal dignity, and clear information.<sup>3</sup>

In this context, nurses are in the spotlight because they concomitantly provide care while working in the administrative sphere of the Brazilian health system. Additionally, nurses – more frequently than any other health worker – are present in situations

where there is an opportunity to implement actions intended to ensure the rights of patients, to advocate for them. The nursing profession is grounded on specific laws that guide bureaucratic, operational and ethical aspects that establish respect of human dignity and the delivery of quality and ethical care, ensuring the human rights and interests of citizens legally protected by law.<sup>4</sup>

Nurses work within the healthcare sphere, however, are also subject to institutional characteristics (mission, vision, values, and goals, among others), whether institutions are public or private. The literature reports that nurses experience, with lower or greater intensity, moral distress, especially when involved in situations in which they are not able to provide humanized care or advocate for their patients. Moral distress intensifies when, due to external pressure, workers are unable to defend the health rights of patients.<sup>5</sup>

Based on the preceding discussion, this study’s objective was to present a theoretical reflection upon the work of nurses in the sphere of patient advocacy, considering the current context of the Brazilian health services.

## METHOD

This descriptive, reflective study was conducted between April and June 2018. It was a requirement of the course “Care delivered in acute situations” of the Graduate Nursing Program at the Federal University of Santa Catarina, Brazil. This study was based on a narrative literature review addressing the topic and on the material recommended on the course’s plan.

The reflections are presented according to two themes. The first is called “Me, nurse, patient advocate?,” which addresses the patient advocate role within the health and nursing field; and the second theme is called “Nursing patient advocacy in the Brazilian context of health,” in which there is reflection upon the Brazilian health system and on how patient advocacy actions take place, or in some cases, why they do not.

## DISCUSSION

### ME, NURSE, A PATIENT ADVOCATE?

Health advocacy, as a nursing responsibility, emerged from social movements that took place in the 1970s. It was intended to allow nurses to have the autonomy to make clinical decisions regarding healthcare delivery. Based on this, nursing workers acknowledged that patient advocacy is a component intrinsic to professional ethics, as the relationship established between nurse and patient is strictly close and the presence of nurses is constant in healthcare settings.<sup>6</sup>

Patient advocacy has been established as a complementary role of nursing workers to promote and defend the interests and wellbeing of patients, ensuring they are always aware of their

rights and have access to information in order to make decisions intended to improve their health and therapy adherence.<sup>6,7</sup>

Therefore, actions related to health advocacy are found in the nursing field, including: protecting patients against interventions they do not desire; allowing patients to decide whether they want a treatment that is not indispensable to their recovery; and enabling patients to make their own choices and decisions in terms of health care and treatments, among others. For this reason, nursing workers need to advocate in favor of patients and the community, by defending public policies and establishing healthy environments.<sup>7,8</sup>

Thus, health education and orientation are seen as an alternative to advocate in favor of patients because the delivery of health information clarifies many doubts patients may have during hospitalization, home care, consultation at a primary health care unit, or during health campaigns, ensuring patients have sufficient information to become autonomous in their decision-making that concerns their own health care.<sup>9</sup>

Another instrument used in the practice of patient advocacy is effective communication. Communication is bi-directional, coming from nurses to patients, family members, team members, and from all these parties toward nurses. This communication allows the establishment of ties of trust and can be a means to promote humanized care based on the effective defense of rights – that is, based on patient advocacy. Nonetheless, the fact that a concept for the role nursing workers play as patient advocates has not been established yet results in a situation in which workers experience many difficulties due to a lack of knowledge of their true responsibilities when it comes to advocating for patients.<sup>9</sup>

Note that patient advocacy performed by nursing professionals is a difficult task involving ethical dilemmas and conflicts with the reality with which they are faced, which restrict their autonomy and professional performance. The reason for this is that patient advocacy actions are not stable; rather, these actions are influenced by other workers (who can be of different professions or the same), by the patients' clinical conditions, as well as the patients' contexts of life and individual characteristics.<sup>6</sup>

Note that the stance nursing workers have to assume is also a difficulty they face, as patient advocacy entices differences of opinion about what would be the best for a given patient. Nurses may take a stance toward a given health intervention proposed to a patient, but such a position may result in a direct conflict with other health workers, and especially between the nursing and medical staffs.<sup>6</sup>

## NURSING PATIENT ADVOCACY IN THE BRAZILIAN CONTEXT OF HEALTH

When considering the nursing profession in the Brazilian context, one has to also take into account the background and

training received by these professionals. Under what educational policy are these health workers being trained in Brazil? Is patient advocacy included in the curricula of healthcare programs? Brazilian health training programs falls short in terms of providing what is necessary from the perspective of patient advocacy. The development of practical skills and competencies, real-world application of simulations, clinical performance (assessing, comparing, gauging), these lead to eyes being trained to see what is imperceptible to the layman. Nonetheless, even though ethics and moral sensitivity permeate these competencies, they are not addressed in the training of these workers. In the debate over the profession's ethical challenges, it is especially the case that patient advocacy should be inherent to and inseparable from health practices over the course of academic training; even more so, because it is characteristic of nursing workers to be protagonists in health services. It is known that the professional practice of nurses within the Brazilian context runs into the internal policies of health organizations (whether private or public organizations) and those of their working environment, and these are factors that negatively influence care delivery. Even though nurses understand patient advocacy issues, they do not feel strong enough to pursue them due to power imbalances existing in their work settings<sup>10</sup>.

Brazilian researchers recently validated the Protective Nursing Advocacy Scale PNAS).<sup>6</sup> Until then, there was no scale in the Brazilian context to identify and measure patient advocacy in the nursing field. This scale was developed by American researchers to measure patient advocacy actions in the Nursing field. It includes questions addressing the actions nurses perform when implementing health advocacy, its potential consequences on the work environment, and the influence of nurses' knowledge and personal values, as well as factors that facilitate or barriers that impede patient advocacy.

This scale is organized around the following constructs: a) advocate actions: which reflect the actions of nurses when advocating in favor of their patients; b) working situations and advocacy actions: which refer to the potential consequences of advocating for patients in the working environment; 3) influences from the environment and education: which present items that address the influence of nurses' knowledge, as well as their personal values, confidence and beliefs; d) facilitators and barriers: consisting of items that indicate factors that either facilitate or hinder the practice of health advocacy in the nursing field, including the work environment as a whole.<sup>6</sup>

The scale validated to the Brazilian health state of affairs revealed contexts that explain the current context in which nurses perform patient advocacy. Negative implications, specific actions, factors that facilitate the practice of advocacy, as well as perceptions of facilitators and barriers hindering the exercise of advocacy, were found. Therefore, a scale validated in Portuguese

is a resource that can enable a better understanding of how health advocacy is practiced by nurses in various health facilities and also in various economic and social contexts in Brazil. The scale's authors note that these two factors significantly contribute to the understanding of beliefs of Brazilian nurses and the actions they perform in terms of health advocacy.<sup>6</sup>

The conclusion is that the Brazilian nursing field is currently facing a challenge to develop and implement protection of patients' right to health, which despite its history, is still a new theme in the academic milieu. The challenge is to implement patient advocacy in the current context of the SUS and understand it as one of the greatest victories of the Brazilian population in terms of right to health, so that the state has the duty to promote and expand health care delivery.<sup>11</sup>

Health professionals specifically working in the institutional sphere of the SUS, experience ethical dilemmas on a daily basis, especially when they play the role of patient advocate in an attempt, often frustrated, to ensure that the right to health is a goal not only pursued by nursing workers, but also by the entire multidisciplinary team. When nurses take a stance as patient advocates, they may experience difficulties arising from the organizational climate without the support of the multidisciplinary team in the face of potential problems that may emerge when taking such a stance, especially situations in which ethics and bioethics are not respected.<sup>12</sup>

Thus, given the current situation of the health field in Brazil, people often seek legal instances to ensure their right to health is effective and in most cases people are successful in their pleas. Legal means, however, may also cause ethical professional dilemmas for both nurses and the multidisciplinary team. The reason is that nurses working in specialized services such as psychiatric facilities or intensive care units (ICU) may encounter problems when advocating for patients when certain actions are determined by a court order, as court orders may not foresee the real situation of health services. When hospitalization in an ICU is determined by a court order, for instance, the ICU nurse needs to reassess all patients to determine those who have the best clinical and hemodynamic conditions to be transferred to a non-intensive care unit. Another example is a psychiatric hospital where nurses need to routinely deal with a backset in the psychiatric reform – decreased structure, cuts in expenses, fewer beds, an increase in psychiatric disorders – and are faced with hospitalization determined by a court order. Such legal means often impose the hospitalization of patients without the guarantee that proper treatment will be provided, that is, the law of demand and supply is unbalanced, and nurses need to act as patient advocates considering this context in an attempt to ensure patients receive the type of care that actually meets their needs.<sup>3</sup>

Nurses working in private health institutions, that is, institutions in which less than 100% of the patients are covered by

the SUS, face another challenge in practicing patient advocacy. When the advocacy of patients, intended to ensure a patient's right to health, goes against an organizational culture, intellectual conflicts may arise, which may result in internal problems and penalties or even the loss of jobs.<sup>13</sup>

Thus, there are situations that weaken the role of nurses as patient advocates in the Brazilian context that are often related to their academic training. Undergraduate nursing programs are still focused on the development of technical and scientific knowledge of patients and their clinical, psychiatric, trauma-related, or obstetrical problems, and also issues related to team coordination and management. Thus, knowledge related to patient advocacy is not clearly and directly addressed. Nurses should be instructed and obtain knowledge related to patient advocacy during academic training rather than only empirically experiencing it when entering the job market.<sup>11</sup>

## FINAL CONSIDERATIONS

First, the history of how patient advocacy emerged in the nursing field and the role of nurses in the health field was presented. Then, two tools to be used by health workers were discussed. These tools can be seen as measures to develop the patient advocate role; nurses sometimes see it as a patient advocate action and other times only see it as a welfare action.

Following that, there was reflection upon the training of nursing workers, highlighting the existence of a gap in the teaching of patient advocacy in that it is not clearly and objectively addressed during nurses' academic training. Patient advocacy actions may be implied in the curricula of undergraduate nursing programs, but these programs do not focus on it; the focus is on the practical nature of care delivery.

A scale was also presented to identify patient advocacy actions and the repercussions of these actions for nurses, considering the current context of the Brazilian health field. This tool certainly needs to be known by nursing workers so they can identify the actual situation of patient advocacy in their working settings, whether they work in private or public facilities.

The conclusion is that the nursing field is on its way to establishing a theoretical foundation for patient advocacy to later ground and concretize this practice and clearly include it in the curricula of nursing programs. The empirical way, as has happened in the working environments of these professionals, opens up space for non-constructive criticism, conflict, intellectual disagreements, penalties, and the risk of nurses losing their jobs, among other situations that may lead these workers to experience moral distress.

The results show that patient advocacy is present – even if it is only incipient – to strengthen human rights of the population, especially those related to health. Patient advocacy

needs to become a working tool adopted by all health workers in both public and private health institutions, in order to implement public health policies to improve health services and to provide appropriate care delivery that effectively meets the needs of communities in general.

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