

# Patientrights and their repercussions on the nurse-patient relationship: a scoping review

Rawany Teixeira Carvalho¹ 
Luciana Neves da Silva Bampi² 
Izabella de Araujo Morais³ 
Lydia Feito Grande⁴

<sup>1</sup>Empresa Brasileira de serviços hospitalares (EBSERH), Brasília, Distrito Federal, Brasil.

<sup>2</sup>Universidade de Brasília (UNB), Brasília, Distrito Federal, Brasil.

<sup>3</sup>Secretaria de Saúde do Distrito Federal (SES-DF), Brasília, Distrito Federal, Brasil.

<sup>4</sup>Universidade Complutense de Madrid (UCM),

#### Corresponding author:

Madrid, Espanha.

Rawany Teixeira Carvalho E-mail: <u>rawanycarvalho@hotmail.com</u>

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#### **ARSTRACT**

**Objective:** to map formally produced content on patient rights that have an impact on the nurse-patient relationship. **Methods**: a scoping review that followed recommendations from the JBI and PRISMA Extension for Scoping Reviews. It involved searching for articles in four databases and an electronic library, texts obtained from the references of selected articles, documents from national and international organizations related to the protection of patient rights and nursing entities and autarchies. Results: thirty-four articles, published between 2002 and 2022, and 11 documents, published between 1974 and 2022, were selected. The topics were grouped into four classes: patient rights - meaning of the concept; tools that materialize patient rights (informed consent and advance directives); characteristics of nurses and the nurse-patient relationship that indicate that these professionals respect patient rights; theoretical framework, currents and ethical principles that support nurses' work. Conclusion: respect for patient rights materializes in actions to defend patients by nurses and in the use of informed consent and advance directives, based on human dignity, theoretical and legal frameworks of human rights and the ethical currents and principles that permeate the profession.

**Descriptors:** Patient Rights; Patient Advocacy; Nurse-Patient Relations; Ethics, Nursing; Review.

# INTRODUCTION

Nurses play an essential role in promoting and maintaining patient dignity, and must provide dignified care, regardless of gender, age, race, socioeconomic status, lifestyle, personality, religion, morals or culture<sup>(1,2)</sup>. Although there is no consensus on what constitutes dignified care, it can be said that it relates to respect and support for patient rights<sup>(2)</sup>. In this context, the nurse-patient relationship, which respects human dignity, contributes to the quality of care provided, protects and favors the recovery of people's health<sup>(2)</sup>.

Compliance with patient rights plays a fundamental role in the development of health systems<sup>(3)</sup>. The concept of patient rights (PR) refers to the application of human rights principles in the context of healthcare<sup>(4,5)</sup>. PR have evolved in response to human rights violations in this environment. In this sense, they do not refer to rights rooted in the consumption structure, but derive from the application of universal and legally recognized human rights principles, with respect for human dignity<sup>(5)</sup>.

In Latin America, some nations, such as Argentina, Chile and Uruguay, are concerned with treating patients as subjects with rights<sup>(6)</sup>. Others, like Brazil, are in the early stages of this discussion<sup>(7)</sup>. In the nurse-patient relationship, although this understanding may be a reality in healthcare practice, as shown in some studies<sup>(1,2,4)</sup>, no systematic mapping on the subject was found in literature. Thus, this research is justified by the need to know how nurses understand and recognize PR, how PR materializes in the nurse-patient relationship, what knowledge and skills are re-

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quired of a professional to act in compliance with PR and on which theoretical framework, trends and ethical principles the action is based.

Considering the above, this study aimed to map formally produced content on PR that have repercussions within the scope of the nurse-patient relationship.

#### **METHODS**

This is a scoping review, with a protocol registered in the Open Science Framework (DOI <u>10.17605/OSF.IO/SBP9R</u>), which followed the recommendations from the Joanna Briggs Institute (JBI) (8) and PRISMA Extension for Scoping Reviews (PRISMA-ScR)<sup>(9)</sup>.

To develop the research question, the PCC<sup>(®)</sup> strategy was used, with P (Population) – Nurses and Patients; C (Concept) – PR; and C (Context) – Nurse-Patient Relationships. Thus, the guiding question arose: what is the formally produced content on PR that has repercussions on the nurse-patient relationship? Based on this question, descriptors were selected that would allow us to identify relevant studies.

The databases Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed and the Scientific Electronic Library Online (SciELO) portal were consulted.

In the MEDLINE, Web of Science and CINAHL databases, the descriptors organized in the following strategy were used: (Patients OR Patient OR Clients OR Client) AND ("Patient advocacy" OR "Patient Rights" OR "Right to Treatment" OR "Right to Treatments" OR "Patients' Rights") AND ("Nurse-Patient Relations" OR "Nurse Patient Relationship" OR "Nurse Patient Relationships" OR "Professional-Patient Relations" OR "Professional Patient Relationship" OR "Contacting Client") AND Nurse.

In the LILACS and SciELO databases, the following search strategy was used: (Patients OR Patient OR Clients OR Client) AND ("Patient advocacy" OR "Patient Rights" OR "Right to Treatment" OR "Right to Treatments" OR "Patients' Rights") AND ("Nurse-Patient Relations" OR "Nurse Patient Relationship" OR "Nurse Patient Relationships" OR "Professional Patient Relationship" OR "Contacting Client" OR nurse).

Studies that included in the title and/or abstract and/or descriptors the expressions "patient rights" and/or "patient advocacy" and/or "nurse-patient relations", available in full text in English, Spanish or Portuguese, published between January 2002 and June 2022, were included. The time frame was determined by the institution of the descriptor "Patient Rights" in 2002. Previously, in the Health Sciences Descriptors (Portuguese Acronym: DeCS) and in the Medical Subject Headings (MeSH), the expression "patient advocacy" was used (1974-2001). However, both expressions were used to retrieve a greater number of studies. Editorials, preprints, books, monographs, dissertations, theses and blogs were excluded.

In accordance with the PRISMA guidelines<sup>(10)</sup>, from 2020, research was additionally carried out on the reference lists of the articles selected in the search on databases and virtual libraries and on documents from websites of national and international organizations that aim to protect PR and representative bodies of nursing and nurses in Brazil and worldwide.

The articles were identified and exported to the Rayyan software (version 2022, Qatar Foundation, Qatar)<sup>(11)</sup>. The titles and abstracts of the identified studies were read and analyzed by two independent reviewers to select eligible articles. If there was disagreement regarding inclusion, a third reviewer performed the assessment

After the initial selection based on titles and abstracts, the studies were read in full by all reviewers, independently, in order to answer the research question and extract data of interest. Through information analysis, the topics covered were identified, which allowed the texts to be grouped into classes.

The reference lists of selected articles were searched in order to find content that could answer the research question. Manuscripts posted on the following websites were also searched for the same purpose: American Hospital Association (https://www. aha.org/); European Commission Public Health (https://commission.europa.eu/topics/public-health\_en); Brazilian National Health Council (In Portuguese, Conselho Nacional de Saúde) (Ministry of Health) (https://www.gov.br/conselho-nacional-de-saude/pt-br); Patient Rights Observatory (In Portuguese, Observatório de Direitos do Paciente) (https://observatoriopaciente.com.br/); Redbioética (Unesco) (https://redbioetica.com.ar/), Brazilian Institute of Patient Rights (In Portuguese, Instituto Brasileiro de Direito do Paciente) (https://ibdpac.com.br/), organizations related to the defense of PR, and guidelines on PR issued by nursing and nursing bodies in Brazil, Federal Council of Nursing (In Portuguese, Conselho Federal de Enfermagem) (https://www.cofen.gov.br/), in Europe (https://enda-europe.com/) and the International Council of Nurses (https:// www.icn.ch/). Additionally, the Brazilian Federal Council of Medicine (In Portuguese, Conselho Federal de Medicina) website was consulted (https://crmvirtual.cfm.org.br/BR) because this body issues the only national document that deals with advance directives. These documents were also recovered.

# **RESULTS**

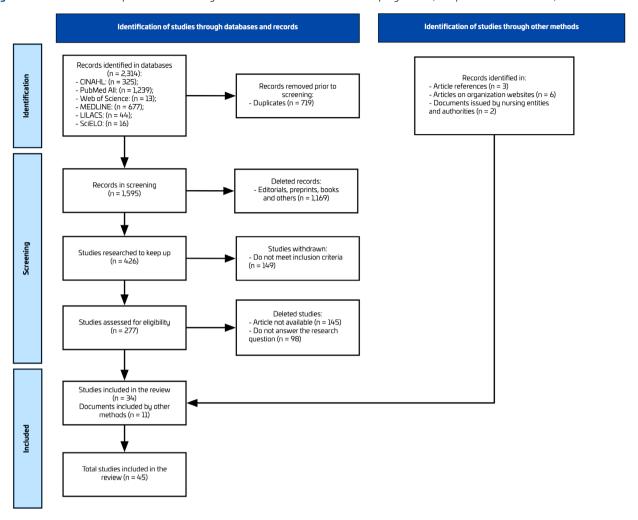
A total of 2,314 articles were identified in the databases and virtual library, and 34 studies were included in the selection processes (Figure 1). The survey of texts from the reference lists of selected articles, on websites defending PR and representative nursing bodies, allowed us to obtain 11 documents.

The 45 texts were grouped into four classes according to the topics covered, namely: 1) Patient rights: meaning of the concept; 2) Tools that materialize patient rights (informed consent and advance directives); 3) Characteristics of nurses and the nurse-patient relationship that indicate that these professionals respect patient

rights; and 4) Theoretical framework, trends and ethical principles that support nurses' work. A text could address topics related to one

or more classes. Table 1 shows the summary of the information extracted from the 45 texts.

Figure 1 - Flowchart for the process of selecting articles and documents for the scoping review, adapted from PRISMA<sup>(10)</sup>, 2023



**Table 1 -** Articles and documents included in the scoping review 2002-2022 by year of publication, country of origin, title of article/document and class(es) of topics covered, 2023

Continue..

Year	Country	Article/document title	Class(es)*
1974	United States of America (USA)	The patient's bill of rights becomes Law <sup>(12)</sup>	1
2002	Italy	European Charter of Patients' Rights <sup>(13)</sup>	1
2002	USA	The nurse's role in end-of-life decision-making for patients and families(14)	2 and 3
2002	Brazil	Ethical aspects concerning nurses' managerial activity <sup>(15)</sup>	2 and 4
2004	USA	Patient advocacy: roles for nurses and leaders <sup>(16)</sup>	3
2006	Iran	Patient advocacy: barriers and facilitators <sup>(17)</sup>	1,3 and 4
2007	Brazil	Psychiatric nursing care in Brazil: legal and ethical aspects <sup>(18)</sup>	1, 2 and 3
2007	USA	Limits of autonomy in nursing's moral discourse(19)	2 and 3
2007	Brazil	Autonomy of elder patients suffering from cancer: the right to know about their diagnoses <sup>(20)</sup>	1, 2 and 4
2008	France	District nurses' attitudes toward patient consent: the case of mechanical ventilation on amyotrophic lateral sclerosis patients: results from a French national survey <sup>(21)</sup>	1, 2 and 3
2008	Brazil	Bioethics of care and the rights of patients and relatives <sup>(22)</sup>	1, 2 and 3

**Table 1** - Articles and documents included in the scoping review 2002-2022 by year of publication, country of origin, title of article/document and class(es) of topics covered, 2023

Conclusion.

Year	Country	Article/document title	Class(es)*
2009	Brazil	Portaria nº 1.820 - Dispõe sobre os direitos e deveres dos usuários da saúde <sup>(23)</sup>	1
2010	Kenya	Nurses' impoliteness as an impediment to patients' rights in selected Kenyan hospitals <sup>(24)</sup>	1, 3 and 4
2011	Finland	Nurses as patient advocates in oncology care: activities based on literature <sup>(25)</sup>	2 and 3
2011	Australia	Ethical advocacy based on caring: a model for neonatal and pediatric nurses <sup>(26)</sup>	3
2012	Brazil	Resolução CFM nº 1.995 - Dispõe sobre as diretivas antecipadas de vontade dos pacientes <sup>(27)</sup>	2
2013	USA	Human rights in patient care: a theoretical and practical framework. Health and Human Rights <sup>(5)</sup>	l and 4
2014	USA	Nursing implications of personalized and precision medicine <sup>(28)</sup>	3
2015	Brazil	Nursing beliefs and actions in exercising patient advocacy in a hospital context <sup>(29)</sup>	l and 3
2015	Turkey	Knowledge and attitudes of nurses regarding patient rights: a Corum/Turkey sample <sup>(30)</sup>	l and 3
2015	England	Nurses' experiences of patients with substance-use disorder in pain: a phenomenological study <sup>(31)</sup>	3
2015	Colombia	Cuidados al final de la vida: una oportunidad para fortalecer el patrón emancipatorio de enfermería <sup>(32)</sup>	3
2016	Belgium	Patients' Rights in the European Union Mapping Exercise <sup>(3)</sup>	1
2017	Ghana	We are the best to stand in for patients": a qualitative study on nurses' advocacy characteristics in Ghana <sup>(33)</sup>	3
2017	USA	Informed consent: ethical and legal considerations for advanced practice nurses (34)	2 and 4
2017	Brazil	Resolução COFEN nº 564 - Código de Ética dos Profissionais de Enfermagem <sup>(35)</sup>	2 and 4
2018	Turkey	Respectful care of human dignity: how is it perceived by patients and nurses? <sup>(2)</sup>	1, 2, 3 and 4
2018	Brazil	Legal predictors in health identified by nurses in the hospital environment <sup>(26)</sup>	1, 3 and 4
2019	USA	Analyzing patients' complaints: awakening of the ethic of belonging <sup>(1)</sup>	3 and 4
2019	Brazil	Patients' rights in Brazil: analysis of legislative proposals and the role of the brazilian system of health <sup>(7)</sup>	1
2019	Spain	Opinions of nurses regarding conscientious objection <sup>(37)</sup>	l and 3
2019	Brazil	Advocacy in intensive care and hospitalization by court order: what are the perspectives of nurses?(38)	1, 3 and 4
2020	Brazil	Mapeo de los derechos de los pacientes en América Latina <sup>(6)</sup>	l and 4
2020	Spain	Problemas bioéticos en la prestación de los cuidados enfermeros durante la pandemia del COVID-19 <sup>(39)</sup>	l and 4
2020	New Zealand	Ensuring informed consent for hearing-impaired patients there are a range of ways nurses can ensure they obtain informed consent from hearing impaired patients <sup>(4,0)</sup>	2
2020	Brazil	Ethics and professionalism in social media: the online behaviour of medical students <sup>(41)</sup>	2 and 4
2020	Australia	Nurses' intentions to respond to requests for legal assisted-dying: A Q-methodological study <sup>(42)</sup>	3
2020	Greece	Paternalism vs patient empowerment: nursing challenges from Spain and Greece <sup>(43)</sup>	2, 3 and 4
2019	Ireland	Code of Ethics and Conduct for European Nursing <sup>(4,4)</sup>	4
2021	USA	Patient advocacy from a perioperative nurse perspective <sup>(45)</sup>	3 and 4
2021	Brazil	Health advocacy in oncology nursing: an integrative literature review(46)	1, 2 and 3
2021	Spain	A qualitative study exploring the patients' perspective from the reserved therapeutic space' nursing intervention in acute mental health units <sup>(47)</sup>	3
2021	Brazil	Ethics and moral distress expressions in intensive care nursing practice <sup>(48)</sup>	3
2021	Switzerland	The ICN Code of Ethics for nurses <sup>(49)</sup>	4
2022	Canada	Universal healthcare coverage, patients' rights, and nurse-patient communication: a critical review of the evidence <sup>(a)</sup>	1, 2, 3 and 4

Note: \* 1= Patient rights: meaning of the concept; 2= Tools that materialize patient rights (informed consent and advance directives); 3= Characteristics of nurses and the nurse-patient relationship that indicate that these professionals respect patient rights; and 4= Theoretical framework, currents and ethical principles that support nurses' work.

# **DISCUSSION**

# Patient rights: meaning of the concept

PR, originating from human rights, manifest themselves in health practices and in the interaction between professionals, pa-

tients and family members/caregivers<sup>(4,5)</sup>. High-quality care includes access to healthcare services, clear information about diagnosis, treatment and prognosis, informed consent, respect for confidentiality and privacy, and continuing care based on the best scientific evidence<sup>(4,5,30)</sup>.

For centuries, a sick individual was seen as physically and morally incompetent, with medical paternalism being understood as a form of beneficence<sup>(4,3)</sup>. In the 1960s and 70s, civil rights movements in the United States of America (USA) and patient associations questioned physicians' power over the patient's body, highlighting the ethical and legal obligation to respect self-determination<sup>(37)</sup>. This change in perspective valued human freedom and autonomy, recognizing patients as active subjects and not an object, valuing rights and participation in decision-making processes in health<sup>(4,3)</sup>.

To preserve PR, laws, rules, codes of ethics and standards of practice for professionals were created<sup>(4)</sup>. The first PR charter was written in 1973 by the American Hospital Association<sup>(12)</sup>. In Europe, Finland, the Netherlands and Hungary were pioneers in adopting specific legislation<sup>(3)</sup>. In 1994, the World Health Organization (WHO) proclaimed the Declaration on the Promotion of Patients' Rights, setting out principles to promote PR in European countries. The 2002 European Charter of Patients' Rights strengthened protection and harmonized care in the European Union (EU) health systems<sup>(13)</sup>.

In 2016, the EU published the European Report on Patients' Rights in the European Union - mapping exercise<sup>(3)</sup>. The document provided an overview of PR in the thirty Member States and pointed out that only Austria, Bulgaria, Ireland, Italy and Malta did not have specific legislation<sup>(3)</sup>.

In Latin America, there is no instrument like the European Charter. PR are scattered across laws and sub-legal regulations, without specific consolidated legislation. The protection of PR is not a priority in Latin American public policies and in 2020, only Ecuador, Chile, Costa Rica, El Salvador, Argentina and Uruguay had specific legislation on the subject<sup>(6)</sup>.

In Brazil, the discussion on PR is still in its infancy<sup>(7)</sup>. The Health Users' Rights and Duties Charter, approved in 2009 by Ordinance 1,820, is an administrative act, without the force of law. There is no national legislation on the subject and some states have limited laws<sup>(7)</sup>. Laws that protect PR can improve health systems by rebalancing the relationship between professionals and patients, encouraging a less paternalistic approach and promoting active patient participation in health decisions<sup>(7),16-20,43)</sup>.

Patient autonomy refers to the exercise of will, the right to active self-determination in therapeutic activity. In some cases, it may be compromised, as in the case of individuals with psychiatric disorders, in which it is necessary to protect the persons and those who live with them<sup>(18)</sup>. Information, competency (to understand information) and freedom (to choose) are essential conditions for autonomy<sup>(22)</sup>. Patients may allow and authorize professionals to deal with them, but this does not grant them the right to decide<sup>(15)</sup>. PR include the practice of being represented; however, decisions made must be in accordance with patients' wishes<sup>(32-34,36)</sup>.

# Tools that materialize patient rights

#### Informed consent

Informed consent is essential in health decisions, being a pro-

cess of communication between professional and patient, which includes information about risks and benefits. It allows patients to decide autonomously about treatments or procedures, functioning as a legal protection tool for patients, professionals and institutions<sup>(15,19)</sup>.

In some situations, the clinical relationship may remain paternalistic and compliance with informational duties and obtaining informed consent by professionals may be fragile<sup>(21)</sup>. There can be a fine line between patient advocacy and paternalism, as in the case of infants who are unable to verbally express their wishes. In this situation, as in others where patients are unable to express their opinion, autonomy is compromised and a more holistic approach must be taken to clarify patients' and families' wishes and needs, in order to effectively advocate for PR<sup>(26)</sup>.

In Spain, where informed consent is legally protected by provisions such as *Ley General de Sanidade* and *Ley Básica Reguladora de la Autonomía del Paciente y de Derechos y Obligaciones en Materia de Información y Documentación Clínica*, it is established that oral and written information must be provided to patients and that informed consent must be obtained before the intervention. Initially, oral and verbal information is provided and then informed consent is recorded in the clinical record, including the nature and purpose of each intervention, the benefits, risks and consequences. In the case of invasive and life-threatening procedures, a specific informed consent document must be signed<sup>(39)</sup>.

Vulnerable individuals, such as older adults and disabled, are more likely to sign informed consent without full understanding, which violates their rights. Therefore, nurses and other healthcare professionals must communicate information effectively and tailored to patients' needs<sup>(40)</sup>.

In the case of use of images, photographs and videos, patient confidentiality and privacy must be safeguarded, through a specific consent form<sup>(41)</sup>.

#### Advance directives

Advance directives aim to promote patient autonomy and improve their experience and satisfaction with end-of-life care<sup>(14)</sup>. They protect PR to choose when they lose the ability to decide<sup>(14,27)</sup>. The concept emerged in response to technological advances and aggressive treatment in ambiguous situations, people with poor prognosis<sup>(14,27)</sup>.

In Brazil, advance directives have no legal basis. There is only one rule from the Federal Council of Medicine, Resolution 1,995 of 2012, which establishes criteria so that any person, of legal age and fully conscious, can define, together with the attending physician, the therapeutic limits in the terminal phase<sup>(27)</sup>.

Respect for advance directives is provided for in the Code of Ethics for Nursing Professionals, in the sole paragraph of Article 42, which reads: "Respect the advance directives of the person regarding decisions about care and treatments that they wish or do not wish to receive, at a time when they are unable to freely and autonomously express their wishes" (35).

# Characteristics of nurses and the nurse-patient relationship that indicate that these professionals respect patient rights

The nurse-patient relationship needs to be meaningful, based on trust so that safe and quality care can be offered<sup>(1)</sup>. Consistent and trusting relationships allow nurses who care for people with chronic or terminal illnesses, for instance, to be in a unique position to help patients and families understand complex information and make difficult decisions<sup>(1,14,42)</sup>.

Nurses help patients recognize their rights. They provide access to information about the benefits and risks associated with treatment, which is essential for patients to be able to provide informed consent<sup>(25)</sup>. Patients have the right to make decisions regarding their care plan, including the right to consent to or refuse treatments or procedures<sup>(34)</sup>. Active patient participation in the decision-making process is the ideal way to achieve excellent nursing care<sup>(17,43)</sup>.

The nurse-patient relationship is strengthened when care is adjusted to patients' needs, with attentive listening being essential<sup>(12)</sup>. Listening to patients helps to avoid unnecessary and uncomfortable treatments, especially at the end of life<sup>(20,21)</sup>. Effective communication is an essential competence of nurses in the health information process<sup>(1,42,43)</sup>.

Some nurses' acts can harm the nurse-patient relationship and respect for PR, such as performing other tasks while answering questions, providing superficial answers or ignoring enquiries, avoiding eye contact, not repeating information when requested, or reprimanding patients. Attitudes such as lack of empathy, inadequate communication, use of a rude tone, inappropriate choice of words, and lack of expression also affect patients' perception of care. Therefore, nurses must promote effective communication, creating a welcoming environment and establishing respectful and empathetic relationships with patients, balancing technical obligations and the ethical commitment to patient care<sup>(1)</sup>.

Patients' leading role in health decisions depends on their ability to communicate, understand information from professionals and deliberate according to their values and goals<sup>(15)</sup>. Lack of communication compromises rights and affects patient safety<sup>(1,15)</sup>. On the other hand, effective communication clarifies doubts and favors decision-making, which is essential in patient advocacy<sup>(26,28)</sup>. It also allows for individualized care, based on mutual respect, collaboration and shared decisions<sup>(28,38)</sup>.

Nurses are seen as patient advocates due to their proximity and length of stay in healthcare facilities, which facilitates the building of partnerships<sup>(2,36)</sup>. Patient advocacy involves empathetic, flexible, and motivated care as well as accountability, commitment, and stress management skills<sup>(16,43)</sup>. Technical knowledge helps in decision-making and supports self-determination, ensuring patients' and families' well-being<sup>(16,46)</sup>.

Patient advocacy is a way of protecting interests and PR and for it to occur it requires experience, knowledge and power<sup>(26,46)</sup>. Personal values, qualifications, moral courage and empathy are essential to exercise these rights<sup>(33,43)</sup>. Nurses have a responsibility

to defend patient rights and well-being, acting as a link between patients, families and care environments, especially in the case of vulnerable people<sup>(29)</sup>. They assist in resolving complex issues by providing information on diagnosis, treatment and prognosis, as well as mediating communication with the team and promoting acceptance of patients' informed choices<sup>(16,46)</sup>.

Patient autonomy is maintained even when they authorize nurses to act on their behalf<sup>(29)</sup>. In critical care, in situations of vulnerability, nurses can intervene on behalf of patients and families, providing guidance on diagnosis, treatment, care and prognosis, always valuing dignified and non-judgmental care<sup>(38)</sup>.

Patient advocacy strengthens the nurse-patient relationship<sup>(26)</sup>. The balance between PR and the reality of care is often guaranteed by nurses who act as patients' advocate, ensuring respect for dignity and autonomy<sup>(18)</sup>. Professionals are prepared for this role through education and organizational leaders must support this training<sup>(14)</sup>.

Nurses with specialization or more experience tend to be better at advocating for patients, as a higher level of education is associated with greater professional autonomy and, consequently, better quality care<sup>(38)</sup>. On the other hand, nurses with less experience often do not recognize themselves as patient advocates<sup>(29)</sup>. Barriers to advocacy include lack of time, motivation, institutional support, norms, and peer loualty<sup>(30,47,48)</sup>.

Nurses may face conflicts when defending PR, which may even compromise the employment relationship<sup>(36,48)</sup>. Many have insufficient training on PR, learning about the topic only after training<sup>(30)</sup>. Knowledge of laws, policies and social relations, as well as continuing education and good team interaction, can make patient advocacy more effective and less confrontational<sup>(36)</sup>.

Nurses need to be trained on PR, while patients should be guided on how to defend their rights without compromising the dignity of professionals<sup>(24,49)</sup>. Effective communication should be central to nursing education, with undergraduate curricula prioritizing this topic and the teaching of PR<sup>(4)</sup>.

The COVID-19 health crisis has raised ethical issues in health-care, such as scarce supplies, lack of staff, and risk of contagion<sup>(39)</sup>. Nurses' fear, fatigue and frustration have a negative impact on patient advocacy<sup>(33)</sup>. Nurses with excessive workload, with scarce resources to perform their duties, with low pay and with reduced participation in the institution's decision-making processes may feel overwhelmed and frustrated, which generates conflicts in clinical relationships and interferes with support for PR<sup>(24-26,28-31)</sup>.

Individual initiatives by nurses are not sufficient to implement PR, since there are institutional, legal, political and social barriers to the normative and operational consolidation of PR. These barriers also interfere with nurses' advocacy for patients<sup>(50)</sup>.

Support from healthcare institutions is crucial to provide autonomy and authority to nurses, empowering them to make decisions and advocate for PR<sup>(50)</sup>. The State must create laws and policies that support these rights. In Brazil, there is no national legislation on PR, although some states, such as Minas Gerais, Rio de Janeiro, São Paulo, Brasília, Paraná, Espírito Santo and Mato Grosso, have limit-

ed laws on the subject(7).

The adoption of laws on human rights recognizes the importance of these rights and the need for a health system that protects them. Among the benefits identified are improvement in healthcare services, increased professional awareness and confidence in staff, greater perception of safety, reduction of legal demands, and greater patient satisfaction<sup>(7)</sup>. Despite the documented benefits, even in Europe, which has had a legislative framework since the early 1990s, the implementation of PR remains a challenge. The difficulty in ensuring such rights in practice is attributed to the fact that PR are unknown to the vast majority of people and the perception of their relevance is still low among patients, family members and healthcare professionals. This fact is combined with paternalism that still predominates in healthcare relationships<sup>(3)</sup>.

This reality was observed in Europe<sup>(3)</sup> and can be transposed to the Brazilian context in an aggravated manner, as there is no national law on PR and the culture of paternalism is much more deeply rooted for historical, cultural and social reasons<sup>(7)</sup>.

Recognition and respect for PR, as well as implementation and monitoring, depend on education and awareness-raising among all, especially healthcare professionals. Nurses play an important role in supporting trade unions and political organizations that defend labor and health rights<sup>(7)</sup>.

In the political-managerial context, nurses have a protective role in PR with management and regulatory bodies, participating in the elaboration, implementation and control of public policies that aim at health-related rights<sup>(51-53)</sup>.

# Theoretical framework, trends and ethical principles that support nurses' work

PR refers to the theoretical and practical application of general human rights principles in the context of healthcare<sup>(4,5)</sup>. Although patient-centered, it is not limited to a particular group of people. The principles of human rights that apply to patient care include the right to the highest standards of healthcare, civil and political rights, the right to liberty, security of person and freedom from torture and inhuman treatment. It also includes the right of socially excluded groups to be free from discrimination<sup>(4,5)</sup>.

Healthcare professionals also face abuse, unsafe working conditions and sanctions for following best practices, which limit freedom. PR recognize professionals as essential actors whose rights must be respected to ensure quality care. The relationship between PR and professional rights is crucial, because without adequate working conditions and rights, professionals cannot provide high-quality care. In this way, the PR approach does not pit patients against professionals or vice versa, but recognizes links that can lead to joint advocacy on systemic issues and state responsibility in care provision<sup>(5)</sup>.

Human rights principles require that services provided to patients meet the standards established in international and national norms and agreements, such as the International Bill of Human Rights (constituted by the International Covenant on Civil and Politi-

cal Rights, the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights) and the Conventions Against Torture, on the Rights of the Child, the Rights of Persons with Disabilities, among others<sup>(4,5)</sup>.

Nurses' responsibility in protecting PR is linked to ethical training. The foundation in deontological ethics, adherence to the code of ethics is fundamental for a good nurse-patient relationship and for the protection of PR<sup>0.5)</sup>. The code of ethics guides nurses, as moral agents, with values and principles that quarantee good care<sup>(44)</sup>.

The ICN Code of Ethics for Nurses, first published in 1953 and last revised in 2021, establishes that nurses' primary responsibility is to patients. Professionals must promote an environment that respects the rights, values, beliefs and customs of individuals. The code also provides guidance on the right to individualized, safe and quality care as well as privacy, confidentiality and consent. It states that nurses must demonstrate values such as respect, justice, empathy and integrity, defending human rights and human dignity<sup>(49)</sup>.

In Brazil, the Code of Ethics for Nursing Professionals, in Article 77, prohibits the participation of nurses in treatments without the consent of patients or legal representatives, except in cases of imminent risk of death<sup>(35)</sup>. The code emphasizes the importance of informed consent, the duty to provide information about risks, benefits and rights, and respect for patient or representative refusal<sup>(15,35)</sup>. It also ensures rights such as confidentiality, privacy and non-discrimination, highlighting the importance of respecting autonomy in health decision-making<sup>(35)</sup>.

The ethics of care has human dignity as one of its deepest values<sup>(2)</sup>. It involves opening up to others, cultivating relationships, communication skills and problem-solving, considering the uniqueness and particularities of each case and each person, without forgetting the whole. Caring and ethics of care give importance to the nurse-patient relationship, enhance contact and make it more human<sup>(2,41)</sup>.

Nurses' performance in the relationship with patients must be based on the ethical principles of autonomy, beneficence, non-maleficence and justice, helping to discern alternatives to resolve ethical problems in care, respecting and promoting PR<sup>(22,43)</sup>. However, nurses' bioethical training needs to be improved, as many are unaware of the possibility of claiming conscientious objection, which allows them to refuse professional obligations for ethical, moral or conscience reasons, as long as it does not harm PR or continuity of care or treatment<sup>(37)</sup>.

The research allowed us to understand what PR means in the context of nursing practice, to know the characteristics of the nurse-patient relationship that reveal professionals' respect for PR, to understand the knowledge and skills that are required of nurses to act, in addition to describing the theoretical framework, currents and ethical principles that support the action. Despite the efforts to include the maximum content on the topic, the option of including only open access online studies may have limited the research content. The knowledge produced, however, may assist in the process of building more effective, humanized and ethical nurse/patient

care relationships that recognize and respect PR.

To strengthen nurses' responsible performance, it is important to establish effective communication and a welcoming environment amidst sincere, respectful and empathetic relationships with patients. Patients should be encouraged to express their needs, desires and concerns and should be aware that their private data, the most intimate matters entrusted to nurses, will be kept and that their rights will be protected. For this to happen more effectively, according to the results of this literature review, it is necessary to promote continuing education programs in healthcare institutions. Training on PR, professional ethics and legal issues related to nursing practice is essential.

# CONCLUSION

Respect for PR is materialized in the nurse-patient relationship, when nurses obtain informed consent for the interventions and care provided, when they respect advance directives in the process of death and dying and, mainly, when they defend patients, i.e., when they protect the interests and PR together with the health team or even before families and caregivers.

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#### Authors' contributions - CRediT

**RTC:** conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; resources; software; validation; visualization; writing – original draft and writing – review & editing.

**LNSB:** conceptualization; data curation; formal analysis; investigation; methodology; resources; software; supervision; validation; visualization; writing – original draft and writing – review & editing.

**IAM:** data curation; formal analysis; investigation; methodology; resources; software; validation; visualization; writing – original draft and writing – re-

view & editing.

**LFG:** visualization; writing – original draft and writing – review & editing.

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