

# Health advocacy and primary health care: evidence for nursing

*Advocacia em saúde e atenção primária à saúde: evidências para enfermagem*

*Defensa de la salud y atención primaria de salud: evidencias para enfermeira*

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## ABSTRACT

**Objectives:** to analyze nursing actions involving health advocacy in the context of primary health care and the consolidation of this right to health. **Methods:** this is an integrative literature review with content analysis of the results on health advocacy and its relationship with nursing in the context of primary health care. **Results:** the content analysis of the seven selected studies resulted in two thematic categories: "Right to health - a complex and progressive consolidation movement in Brazil" and "Advocacy in health and nursing". **Conclusions:** despite the difficulties in defining the concept of health advocacy, nurses, in their practice, act with innovative alternatives to daily conflicts, exercising the users' right to health in their relationships with health team members and the community. **Descriptors:** Patient Advocacy; Primary Health Care; Patient Rights; Nursing; Review.

## RESUMO

**Objetivos:** analisar as ações de enfermagem que envolvem advocacia em saúde no âmbito da atenção primária à saúde e a consolidação deste direito à saúde. **Métodos:** trata-se de um estudo de revisão integrativa da literatura com análise de conteúdo dos resultados sobre a advocacia em saúde e sua relação com a enfermagem no contexto de atenção primária à saúde. **Resultados:** da análise de conteúdo dos sete estudos selecionados, originaram-se duas categorias do tema: "Direito à saúde – um movimento complexo e progressivo de consolidação no Brasil" e "Advocacia em saúde e Enfermagem". **Conclusões:** apesar das dificuldades de definição do conceito de advocacia em saúde, os enfermeiros, em sua prática, atuam com alternativas inovadoras aos conflitos diários, exercendo o direito à saúde dos usuários em suas relações com membros da equipe de saúde e a comunidade. **Descritores:** Advocacia em Saúde; Atenção Primária à Saúde; Direito à Saúde; Enfermagem; Revisão.

## RESUMEN

**Objetivos:** analizar las acciones de enfermería que involucran la defensa de la salud en el contexto de la atención primaria de salud y la consolidación de este derecho de salud. **Métodos:** esta es una revisión integrativa de la literatura con análisis de contenido de los resultados sobre la defensa de la salud y su relación con la enfermería en el contexto de la atención primaria de salud. **Resultados:** del análisis de contenido de los siete estudios seleccionados se originaron dos categorías del tema: "Derecho de salud: un movimiento complejo y progresivo de consolidación en Brasil" y "Defensa en salud y enfermería". **Conclusiones:** a pesar de las dificultades para definir el concepto de defensa de la salud, las enfermeras, en su práctica, actúan con alternativas innovadoras a los conflictos diarios, practicando el derecho de los usuarios a la salud en sus relaciones con miembros del equipo de salud y la comunidad. **Descriptorios:** Defensa de la Salud; Atención Primaria de Salud; Derecho a la Salud; Enfermería; Revisión.

## INTRODUCTION

The standards of human rights protection are built and rebuilt, initially gaining consolidation as a reaction to a series of historical situations of abuse in which the idea of human disposability prevailed. They are based on the principle of human dignity and seek to protect people's self-respect, self-awareness, and self-identity.

Nevertheless, human rights are constantly violated, restricted or extinguished. World Bank data indicate that about two billion people live in extreme poverty in the world and that child mortality in low-income countries is almost ten times higher than in developing countries<sup>(1)</sup>. Poverty remains a reality for billions of people worldwide and is also striking in Brazil. According to Brazilian Institute for Geography and Statistics (IBGE) data<sup>(2)</sup>, between 2002 and 2012, the Southeast concentrated more than half of the percentage of the Gross Domestic Product (GDP), with 55% while, in contrast, the North accounted for only 5% of GDP. In this scenario, when comparing the Municipal Human Development Indices (MHDI) in Brazil for 1991, 2000 and 2010, among 5565 cities, the twenty best MHDI came from cities in the states of São Paulo, Santa Catarina, Espírito Santo, Paraná, Rio Grande do Sul, Minas Gerais, and the Federal District. Of these twenty, almost half came from São Paulo cities. Among the twenty worst MHDI were cities in the states of Piauí, Maranhão, Amazonas, and Pará.

Intense social inequalities limit the minimum conditions for effective human and social development. In this context of contradictions, the rights are to be protected by law, but also and above all to be accomplished in practice by the State and civil society<sup>(3)</sup>. In other words, the "discourse" of the rights needs to be reflected and translated into the real power of individuals and groups in society to determine the meaning of their potential in the social context. The rights are and have to be maintained through their constant renewal as an action, allowing the empowerment of people, not only as the object of the rules but as the actual subjects of the right<sup>(4)</sup>.

As a claim to these rights, as outlined by the Health Sciences Descriptor (DeCS), the term health advocacy is presented as individual, group and community actions to influence authorities and individuals regarding the right to health. In this sense, access to health is one of the fundamental human rights guaranteed by the Constitution, which enables Brazilian citizens to demand from the State comprehensive living conditions with complete biopsychosocial well-being and quality of life<sup>(5)</sup>.

The practice of health advocacy by nursing originates in the 1970s, arising from social movements and based on ethical, legal and moral aspects of the profession. It is closely associated with support for the individual autonomy of patients, family, and community, as well as with the protection of their right to self-determination in decision-making situations in health and disease processes. In the international scenario, studies highlight the different contexts in which nurses and the multiprofessional health team act in health advocacy<sup>(6-7)</sup>.

From this perspective, in the context of primary health care, the specific objective is to ensure that the rights are available to all individuals and families in the community through their

full participation in all stages of health development and promotion. The role of nursing in the context of advocacy and primary health care reveals the essence and direct relationship of patient care; its practice also comes with barriers though, which hinder its full development and satisfaction<sup>(7-8)</sup>. In addition, the promotion of the well-being and interests of their patients, family, and community is an integral part of nurses' efforts, so as to ensure that they are aware of their rights and have access to information for decision making.

Three essential attributes are highlighted in the concept of nursing advocacy: valuing patients' right to self-determination; informing patients and preparing them for decision making; defending the patient, family and health team, so that their desires and needs are met<sup>(7)</sup>. In this sense, in a systematic literature review of 89 selected studies in the period 1990–2003, nursing advocacy activities were identified, such as informing patients, assisting in patient decision making, and protecting patient rights and safety. The study also permitted observing the difficulty in the definitions and activities of health advocacy though<sup>(9)</sup>. Nursing advocacy is also employed to signify, through ethics, the patient's assurance and decision-making power in line with his or her wishes when performing a procedure or technique<sup>(10)</sup>.

The challenge of defining the nurses' actions in health advocacy is a complex task, as it is difficult to understand the term health advocacy and its actions are not static and fixed in health services. These are actions related to individual characteristics, organizations, clinical situations and operating environments.

## OBJECTIVES

To analyze nursing actions involving health advocacy in the context of primary health care and the consolidation of the right to health through health advocacy.

## METHODS

This is an integrative literature review study with content analysis of the results obtained. In this sense, to collect and select the collection and selection of the material for analysis, an integrative literature review was performed in order to search the most recent studies on the subject and to synthesize the various selected studies, permitting general conclusions on a particular study area. This review method consists of elaborating the research question, sampling or literature search for primary studies, data extraction, evaluation of the included primary studies, interpretation of results, presentation of the general synthesis of the review<sup>(11)</sup>.

In this sense, the following review question was delimited: "What is the scientific evidence in nursing about health advocacy in the context of primary health care?". The initial keywords for the search were: *advocacia em saúde/health advocacy/defensa de la salud; enfermagem/nursing/enfermería; atenção primária à saúde/primary health care/atención primaria de salud*.

The search for the studies took place from August to November 2017, in the following databases: National Library of Medicine National Institutes of Health (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Latin American

and Caribbean Literature in Health Sciences (LILACS); SCOPUS and Scientific Electronic Library Online (SciELO). The controlled descriptors selected from the Health Science Descriptors (DeCS) of the Virtual Health Library (VHL) and MeSH Database were health advocacy; nursing; primary health care.

The terms were combined in different ways to ensure a broad search. The terms were crossed in combination with the Boolean operators AND and OR, according to the search system of each database. Studies were included in English, Spanish and Portuguese; between 2012 and 2017; with quantitative and qualitative designs, primary studies, systematic reviews, meta-analyses and/or meta-syntheses. Event summaries, books, theses/dissertations, websites, and media advertisements were excluded.

The search and selection process for studies in this review is presented in Figure 1, according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)<sup>(12)</sup>.

After exhaustive reading of the titles and abstracts of the 250 studies found, 15 studies were selected because they met the established inclusion criteria. Of these, after reading the full versions of the studies, seven final studies were selected for this review. In this sense, to interpret the data, the information extracted from the selected studies for eligibility was synthesized<sup>(11)</sup>, using an instrument structured by the researchers, which included the study title, authorship, journal, year of publication, place of study (country, city, region), objective(s), detailed content on health advocacy, theme studied in Nursing, main results and conclusions found.

Based on the results of this review, the steps of skimming and selection of content analysis units were performed. Content analysis consists of examining the content of narrative data to identify prominent themes and patterns among the texts analyzed. This qualitative data analysis method comprises a set of research techniques whose objective is to search for the meaning or the senses of a document<sup>(13-14)</sup>. From the analysis steps, the categorization process was performed by grouping the analysis units and the categories that were defined<sup>(14)</sup>.

Then, the sets of subjects relevant to the theme of the selected studies were grouped and the citation frequency of the content was measured. By grouping the findings in the content analysis, the categories related to the theme were delimited to interpret and understand the important meanings extracted from the content analysis of the studies<sup>(14)</sup>.

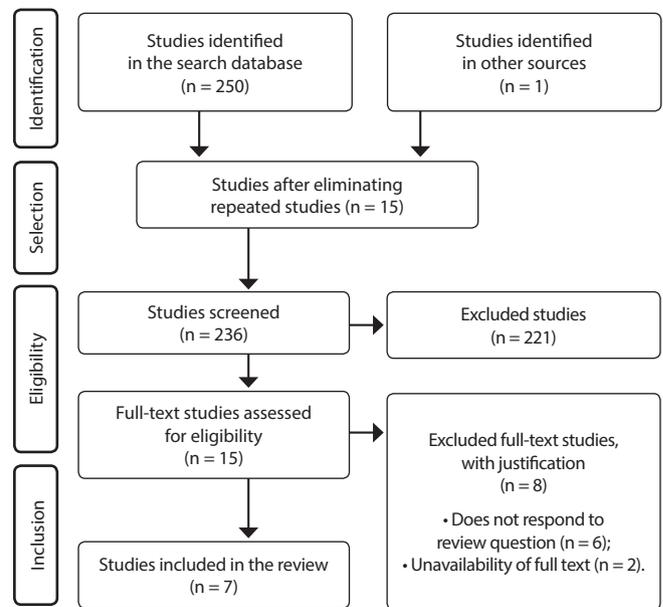


Figure 1 – Flowchart of crosschecks and search results

## RESULTS

The seven selected studies were published from 2012 to 2017 and written in English and Portuguese. Chart 1 presents the data of the studies analyzed according to year, author, journal name, country, type of study, title and descriptors.

After interpreting the data from the selected studies, the content analysis of the seven studies was developed according to the design of the health advocacy theme, the relationship between health advocacy and nursing, the citation frequency in the texts, as shown in Chart 2.

Chart 1 – Studies found according to year of publication, authorship, journal name, country of study, study design, title and descriptors

Study	Year	Authorship	Journal	Country of Study	Descriptors
1	2012	Pavlish C, Ho A, Rounkle AM <sup>(15)</sup>	J Nurs Ethics	Democratic Republic of Congo	Advocacy; Ethnography; Gender-Based Violence; Human Rights; Nursing Ethics
2	2014	Cole C, Wellard, S, Mummy J <sup>(16)</sup>	Nurs Ethics	Australia	Advocacy; Autonomy; Nursing; Relational Autonomy
3	2014	Josse-Eklund A et al. <sup>(17)</sup>	Nurs Ethics	Sweden	Nurse–Patient Relationship; Nursing Qualities; Organisation; Patient Advocacy; Phenomenography
4	2015	Tomaschewski-Barlem J et al. <sup>(18)</sup>	Rev. Latino-Am. Enfermagem	Brazil	Health Advocacy; Nursing; Nursing Ethics; Validation Studies
5	2017	Tomaschewski-Barlem J et al. <sup>(19)</sup>	Texto Contexto Enferm	Brazil	Health Advocacy; Nursing; Nursing Ethics
6	2017	Eaton M et al. <sup>(20)</sup>	Nurse Educator	United States	Health Policy Advocacy; Health Professions Education; Interprofessional Education; Political Astuteness; Team-Based Learning
7	2017	Rosa W <sup>(21)</sup>	Public Health Nurs	United States	---

**Chart 2** – Content analysis of the seven selected studies according to the relevance of the theme on health advocacy, the citation frequency and the relationship between health advocacy and nursing.

Study	Theme discussed on health advocacy	Citation frequency in the text: Health advocacy	Citation frequency: advocacy	Relationship between health advocacy and nursing
1	Human Rights-Based Advocacy	---	54	Moral formation of nursing, which aims to promote health, people's rights and wellbeing.
2	Patient Advocacy; Advocacy In Healthcare	---	24	Patient autonomy and advocacy in nursing.
3	Patient Advocacy	---	67	Nurses' characteristics, such as professional competency, organizational skills, motivation at work and experience, are considered as facilitators of health advocacy.
4	Health Advocacy; Patient Advocacy	24	75	Protective Nursing Advocacy Scale (PNAS) developed and used to measure health advocacy beliefs and actions in nursing.
5	Patient Advocacy	1	68	Moral distress and its relationships with the exercise of patient advocacy.
6	Health Policy Advocacy	1	30	Nurses and other health professionals, in the ethical perspective, act in defense of the practice of the health policy based on equality and social justice.
7	Local to Global Health Advocacy	1	2	Nursing advocacy in public health acts in interracial violence, implications of climate changes, poverty as an indicator of long-term health risks.

Based on the content analysis of the theme in the selected studies, two categories were extracted and constructed: "Right to health – a complex and progressive consolidation movement in Brazil" and "Advocacy in health and Nursing".

## DISCUSSION

Health advocacy represents content addressed in national and international literature, identified in studies of health disciplines, especially nursing. This relevance is demonstrated in publications from international nursing-related organizations and is underlined by the World Health Organization's Global Strategic Direction for Strengthening Nursing and Midwifery 2016-2020; Global Advisory Panel on the Future of Nursing by Sigma Theta Tau International (2017)<sup>(21)</sup>; and by the International Council of Nurses<sup>(22)</sup>.

In this sense, the findings of this study (Chart 1) corroborate the publications of the abovementioned international agencies. The studies found were recently published among nursing and other researchers, demonstrating the magnitude of the subject in different sciences and in different geographical areas.

The results also show (Chart 2) that the content analysis of the scientific literature addresses health advocacy in a set of terms that encompass its definition, particularly human rights and patient health, health policies, local and global. In that context, two categories were identified on the theme: "Right to

health - a complex and progressive movement of consolidation in Brazil" and "Advocacy in health and nursing", presented below.

### Right to health - a complex and progressive movement of consolidation in Brazil

The constitution of modern citizenship comprises three main elements: a) civil rights, which represent the "rights necessary for individual freedom - freedom to come and go, freedom of the press, freedom of thought and faith, the right to property and to close valid contracts, and the right to justice"; b) political rights, which include participation "in the exercise of political power, as a member of a body vested with political authority or as an elector of the members of that body" and c) social rights, with minimum economic well-being and guarantee of the right to participate fully in the social heritage and to live the life of a civilized being according to the prevailing standards in society"<sup>(23)</sup>. With regard to the effectiveness of these rights, civil and political

rights have immediate application; Social rights, on the other hand, are progressively applied, as they depend on the resources available in each location, a fact that may hinder their full consolidation.

In that perspective, the right to health is a social human right that, due to its complexity, makes it more difficult to fully guarantee its content and scope. It is a right because of the value that health represents for the development of people's capacities, personality, life projects, as well as for the development of the community. It represents a fundamental human right, directly linked to the right to life, moral, mental and physical integrity, which are the foundation for the exercise of all human rights. Health is, therefore, an essential and prerogative condition of people's dignity as individual and social beings<sup>(21-22)</sup>.

In 1978, the Alma Ata Conference represented a milestone for the conception of health as a right, mobilizing health professionals and institutions, governments and civil society organizations that considered social justice and the right to better health for all, participation and solidarity. As a result, the goal "Health for All" was established, with primary health care as the primary approach to its development. This movement was strengthened and, in 1986, during the First International Conference on Health Promotion in Ottawa, Canada, the idea of health as a socially produced good was consolidated, with the following fundamental requirements for its achievement: housing, education, food, income, a stable ecosystem, sustainable resources, social justice and equity<sup>(24)</sup>.

In 2003, the Pan American Health Organization, a representative body of the World Health Organization in the Americas, reevaluated the values and principles that a few decades earlier inspired the Alma Ata Declaration to develop its future strategy and programmatic guidelines for primary health care. The resulting strategy was presented in the 2007 *Renewing Primary Health Care in the Americas* document, which provided a renewed vision and meaning for the development of health systems based on Primary Health Care and established that countries should each find their own way of building a sustainable way to base their health system in accordance with this approach<sup>(25)</sup>.

In Brazil, the 1988 Constitution guaranteed the population's right to health by explicitly determining that health actions and services integrate a regionalized and hierarchical network and constitute a Unified Health System (SUS), organized according to decentralization guidelines, comprehensive care, and community participation<sup>(5)</sup>. In this context, primary health care incorporated the principles of the health reform in the country, leading the SUS to the adoption of Primary Health Care (PHC) to emphasize the reorientation of the care model, based on a universal and integrated health care system<sup>(23-24)</sup>.

This social reality gave rise to a type of practice aimed at defending the right to health, called health advocacy, understood as a set of social, economic, political and legal actions, coordinated and aimed at the prevention, protection and promotion of the right to health, organized by specific social actors who, through concrete actions, seek to obtain from those responsible the practice or abstention from an action in favor of individual, collective and public health<sup>(25)</sup>. Among these groups, nurses and nursing staff are emphasized as key professionals for the practice of innovative initiatives to assess the needs of individuals and populations, aiming at community development and work in partnerships to strengthen health.

Several challenges persist and indicate the need to articulate strategies for access to other levels of health care though, in order to guarantee the integrality principle, as well as the permanent need to adjust local health actions and services, aiming at increased apprehension of the population's health needs and the overcoming of inequities between the regions of the country. It is also emphasized that, despite being a universally recognized value, health generally is not considered a political priority in terms of actual investments, which makes the population even more vulnerable and susceptible to abuse. As a consequence, individuals do not identify themselves as holders of the right to health, which impedes the exercise of their full citizenship. In this scenario of contradictions and possibilities, the potentialities of health advocacy practiced by nursing constitute an important element for the effective practice of health as a human right.

### Advocacy in Health and Nursing

Health advocacy is linked to the movement for the assertion of human rights, which is based on the concept that, through awareness as human beings, one can participate in the process of forming rules of living together in society. Thus, at the same time, everyone is a member of society and the object of its rules<sup>(26)</sup>.

The definition of nursing advocacy has been a goal of the profession itself, especially considering its insertion in different

nursing ethics codes, including the Ethics Code of the International Council of Nurses<sup>(22)</sup>, which describes it as a key function for nursing. As a consequence of this movement, nursing has placed itself alongside Law and Medicine, among the only professions that formalized advocacy as one of their functions, moving away from a model focused on organizational compliance with advocacy directed at health service users.

Considerable literature exists studying nursing advocacy and nurses' role in the rights of health service users<sup>(15-22)</sup>. Despite these studies, there are still gaps in the conceptualization of nursing law, which for some makes it an ambiguous and abstract term, making its practice difficult<sup>(15)</sup>. Thus, the lack of a model that defines parameters for advocacy in professional practice further enhances existing doubts and hinders its practice by nurses.

In general, health advocacy involves, on the one hand, the vulnerability of the individual and, on the other, humanity in the relationship between nurses and their patients. From this perspective, the nurse acts to make the health service users exercise their rights, especially that of self-determination. There are, then, some inherent elements of advocacy: 1) the existence of some kind of difficulty, conflict or situations involving ethical choices that generate the need for health advocacy; 2) the proactivity of the nurse; 3) nurses' actions in favor of health service users, usually mediating their relationships with family, health team members and other sectors of society<sup>(20-22)</sup>.

Therefore, advocacy has turned into an ethical ideal, based on the assumption that the nurse knows the patient, being responsible for the continuity of care<sup>(16,18)</sup>. Within the family health strategy, nurses are even closer to the users, their families, and the community, sharing and experiencing their problems and difficulties. Thus, in everyday life, nurses are explicitly or implicitly called upon to act for the service users' right to health when, for example, they protect them against unnecessary treatment, unwanted interventions, or especially when they inform the service users about their rights, with a view to informed decisions on their future actions. Nurses need to face conflicts and be ready to negotiate and defend changes in the status quo, seeking to grant visibility and voice to those who cannot exercise their rights and autonomy<sup>(19-21,27)</sup>. Health service users are therefore vulnerable, uninformed and intimidated, and their rights are often overlooked<sup>(28)</sup>.

Through health advocacy, nurses exercise their empathy, ethical values, assertiveness and persistence to deal with their own fear, fatigue, frustrations and stress in an environment of potential conflict among team members, lack of economic resources, infrastructure and the existence of traditional models of organizational management and health care itself, which may jeopardize the safety of their work<sup>(20-21,28)</sup>. The work burden and lack of recognition by patients impair their performance of the advocacy role though. The patients' ingratitude may lead to these professionals' dissatisfaction<sup>(29)</sup>.

The users' health right claims vary, with nurses taking on more passive or active attitudes. From this perspective, it is crucial that nurses move away from a paternalistic orientation and act towards a user-centered orientation of the health service. With the necessary information at hand, the users can seek alternatives for access and for the exercise of their rights.

Nevertheless, access to health information and the right to health is not given and needs to be constantly built in different health services, with the participation of nurses. For the sake of a better understanding, for example, a study aimed to identify the knowledge of users of a Primary Health Care Unit about their right to health information. Twenty-two users participated in this study, whose results showed difficulties in accessing information on diagnosis, tests, medications, risks and benefits of treatment; the feeling of disequilibrium in the existing power relations between the user and the health professionals; user dissatisfaction about not receiving the necessary information, and excessive bureaucracy in care<sup>(30)</sup>.

Thus, nurses can and should play a more active role through health advocacy in order to change this scenario. Therefore, it is essential that they are prepared for assertive communication, possessing information and knowledge about their rights and duties towards users, families, employment organization, class organizations, community, and society in general.

### Contributions to the Nursing area

In short, the characteristics of self-confidence and the strength of their conviction are important influences on advocacy and facilitate the interaction between nurses and their service users through genuine dialogues in a context of openness, availability, and exchange<sup>(20)</sup>. In this context, several barriers exist for the practice of nursing advocacy in different contexts, including primary care.

In these situations, nurses are fully able to act as actual educators, influencing decisions that result in more effective health services, respecting equity, facilitating inclusion and aiming for the rebalancing of power, through information that supports the exercise of rights and results in the service users' autonomy in this process.

In this scenario, the users' exercise of citizenship is directly related to their empowerment. Empowerment is understood as the process by which those in power, in this case, health professionals and nurses, favor others, users, to gain and use the power necessary to make decisions that affect themselves or their lives<sup>(21)</sup>. The promotion of the individual's autonomy through information

plays a fundamental role in the self-transformation process of the person, as it favors an environment of change in order to offer autonomy to the individuals involved<sup>(22-23)</sup>. In this context, nurses, through advocacy, can facilitate the displacement of the user from the category of a mere receiver, placing him/her as a central actor in the appropriation process of information, turning into an active and participatory being.

### Study Limitations

Despite the conceptual and practical evolution, some studies appoint limitations for nursing advocacy. The difficulties include the economic imperative and working with scarce resources, making health a commodity, especially in this neoliberal model that increasingly restricts the role of the state. We also highlight the difficulties experienced due to differences in power among health team members, the lack of operational autonomy and authority in the context of health organizations, so that nurses can formally structure their knowledge and practice, aiming to implement advocacy actions for health service users and the community.

### CONCLUSIONS

To cope with these challenges, nurses need to seek alternative paths, grounding their claims and arguments in scientific evidence and data. In this scenario, technical skills are paramount if associated with knowledge and relational skills.

On the other hand, despite the difficulties in defining the concept of health advocacy, nurses, in their practice, seek innovative alternatives daily to cope with the different problems that arise and already claim the health rights in their relationships with the service users and the community, joining forces with different team members. In this sense, it is important to name these actions health advocacy, giving visibility to this nursing function, which is as important as all other already accepted functions and reveals the commitment and passion of nurses even further in their daily struggle for the integrality of health care and the accomplishment of the right to health in the country.

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