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Agenda for patient-centered care research in Brazil

Juliana Loureiro da Silva de Queiroz Rodrigues (http://orcid.org/0000-0002-2005-0377) [1]
Margareth Crisóstomo Portela (http://orcid.org/0000-0002-9858-9276) [1]
Ana Maria Malik (https://orcid.org/0000-0002-0813-8886) [2]

Abstract *Patient-centered care is an incipient movement and its practice still faces obstacles in the Brazilian health system, where it is not extensively identified as healthcare quality realm. Thus, this paper aims to establish a patient/person-centered care research agenda to support its implementation in the country's healthcare services. A panel was held with nine experts to grasp different views on the subject. The face-to-face discussion was supported by a document systematizing an initial agenda proposal and a brief presentation of the patient-centered care concept and theoretical elements that underpin its practice. Panel participants defined a set of items to be explored in studies to identify implementation and to strengthen and to measure strategies for patient-centered care in the Brazilian context.*

Key words *Person-centered care, Patient-centered care, Quality of care.*

[1] Escola Nacional de Saúde Pública Sérgio Arouca, Fundação Oswaldo Cruz. R. Leopoldo Bulhões 1480, Manguinhos. 21041-210 Rio de Janeiro RJ Brasil. juebe28@gmail.com
[2] Escola de Administração de Empresas de São Paulo, Fundação Getúlio Vargas. Bela Vista SP Brasil.

Introduction

Donabedian[1] already emphasized interpersonal relationships as a fundamental healthcare component, which suggests that the centrality of healthcare in the subject is not new. To date, it does not correspond to a precise concept[2] but has gained momentum in this millennium with the inclusion of "patient-centered care" as one of the goals of a plan to improve the quality of healthcare in the United States, as set forth in the "*Crossing the quality chasm: A new health system for the 21st century*" report of the Institute of Medicine (IOM). In this document, patient-centered care is defined as "respectfully providing care, responding to the needs, preferences and values of the assisted, with the assurance that those values guide all clinical decisions"[3].

Currently, a diversity of terms translates the centrality of healthcare in the subject. Such words are interchangeable and their use may vary according to the context in which the provision of health services occurs[4].

There is evidence that the practice of patient-centered care has positive effects on clinical outcomes, stimulating cooperation and enabling support and consolidation of their rights[5]. It is a care model that seeks to break with the remaining paradigms of the biomedical model and overcome the fragmentation of care[6].

However, the implementation of this practice of care is a significant challenge for health services[5,6]. This is attributed to paternalism, beliefs and cultures of the population; change-resistant professionals because they believe they already practice patient-centered care; few empirical driving studies; lack of leadership; and the infrastructure of the environment[5,7].

The principles guiding the practice of patient-centered care are dignity, compassion and respect; coordination and integration of care; personalized care; self-care support; information, communication and education; physical comfort; emotional support, fear and anxiety relief; involvement of relatives and friends; transition and continuity; and, more recently, access to care[8].

It is appropriate to propose an agenda of elements to be prioritized in the research area, to the effective implementation of patient-centered care in health services, considering the importance of the theme and the peculiarities of the Brazilian context. In this regard, this paper aims to show an agenda that supports the development of studies capable of pointing out strategies for the implementation of "patient-centered care" in Brazilian health services.

Methods

A panel of experts was held to grasp different theoretical and practical views on "patient-centered care". Eleven professionals were invited to the panel, considering affinity with the theme and work in the provision of health services in private or public establishments, either in activities of planning and coordination of actions in SUS management institutions or academic activities. The representation of categories was not a concern in the choice of participants. We also considered relevant the participation of a patient engaged in the fight for the protection of patients, searching for this individual in an association of patients (Chart 1).

After the participants' consent, the debate was recorded to safeguard all the technical inputs, linking them to the proposed discussion topics (Chart 2), and support the analysis of the panel's outcomes.

In contact with the Research Ethics Committee (CEP) of the institution where the panel was promoted, it was argued that members of a group of experts are invited to provide professional opinions, based on their knowledge and experience. Thus, they are not in a condition of vulnerability, justifying non-submission to said Committee. After consultation of the CEP with the National Research Ethics Committee, this argument was accepted.

Results

The experts' meeting was held on May 21, 2015, lasting six hours. Although all the guests expressed interest, only nine experts participated in the panel. As a starting point, a brief presentation of the concept of patient-centered care, theoretical elements and the relevance of discussing the topic in the Brazilian and international contexts was made. The panel reached the consensus that the theoretical framework of the discussion about patient-centered care is closely related to other realms of the quality of healthcare, incurring issues relevant to the actual current complexity of care.

Chart 3 systematizes the final result of the debate that has taken place, some of which are highlighted below.

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Chart 1. Composition of the Panel of Experts

Profile	Participant
Patient Association Representative.	X
Lawyer. Professor and Bioethics and Human Rights expert.	
Doctor. Professor and Researcher in the field of Health Management.	X
Doctor. Municipal manager.	X
Nurse. Ph.D. in Public Health. Health Surveillance and Patient Safety expert.	X
Doctor. Ph.D. in Public Health. Professor and Researcher in the field of Healthcare Quality.	X
Doctor. Intensivist and Quality Advisor in a large specialized hospital.	X
Doctor. Ph.D. in Public Health. Endocrinology expert working in private practice.	X
Occupational Therapist. Master in Public Health with a dissertation dedicated to the topic of patient/person-centered care.	X
Doctor. Ph.D. in Public Health. Professor and researcher in the field of Bioethics	
Doctor. Ph.D. in Public Health. Geriatrician active in Primary Care, in the public sector and the private sector.	X

Chart 2. Points covered in the base document submitted to the panel of experts.

Definition of a research agenda and approach of patient-centered care in Brazil		
Objective	To establish an agenda for the research and approach of patient-centered care within the health services, starting from the appreciation and indication (or not) of a preferred terminology designation.	
Proposed strategy	Brief discussion on the designations of "patient-centered care" and "person-centered care", to indicating a chosen term to be recommended in the Brazilian health context, followed by a debate on points to be included in the agenda.	
Expected outcomes	Establishment of the agenda and the elaboration of a paper containing the systematization of the work performed, where all panel participants are coauthors.	
Agenda submitted to the panel		
Item	**Justification**	**Main questions**
The concept of "patient-centered care."	Concepts facilitate the operationalization of health interventions and practices.	What are the patient-centered care attributes that must be prioritized in the Brazilian healthcare reality, considering territorial diversity?
Contextual aspects relevant to the implementation of patient-centered care.	Recognition that contextual factors influence the success (or not) of interventions, towards improving the quality of healthcare and having a dynamic interaction with such actions.	What are the contextual aspects that facilitate or hinder a culture towards the provision of patient-centered healthcare? Does the provision of patient-centered care vary according to the effects of these contextual aspects?
The political strategies for implementing patient-centered care as a realm of healthcare quality in Brazil.	Brazil does not have a health policy that fully recognizes and supports person-centered care as a realm of the quality of health services.	Should a policy be established in this regard? What strategies would be appropriate in the three spheres of government in the institutional, healthcare, financing and work management contexts towards developing the workers' skills?
Communication between health professionals and patients	Communication is key to any relationship. The way it is developed can determine the success or failure of the relationship between health professionals and professionals and patients.	What are the challenges for the development of communication? How can we improve communication among health professionals and between professionals and patients to promote patient-centered care?

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Chart 2. Points covered in the base document submitted to the panel of experts.

Agenda submitted to the panel		
Item	**Justification**	**Main questions**
Sharing decisions as an element of patient-centered care.	Sharing decision-making in health services is burdened by significant challenges: weak communication, professional-centered practice, cultural and organizational aspects, shortage of human resources, and service overload can contribute to care with low participation by patients and families and more focused on institutional and health professionals' interests.	How do we overcome the resistance of health professionals? How do we deal with issues such as the disproportionality of human resources against demand? What limits are essential, from the patient's point of view, for the sharing of decisions?
Contextual aspects interfere in the continuity of care and adherence to the therapeutic plan	Health practices interact dynamically with internal aspects, inherent in the organization of health and external actions and services, characterized by the influence of other sectors of society, individual, collective and cultural factors of a community.	How do cultural aspects and different conceptions of health interfere with the continuity of healthcare? To what extent the way in which the health system is organized is conducive to or hinders the continuity of care?
The relationship between integrality and patient-centered care.	Integrality is one of the SUS principles that should guide all health practices.	Does the practice of patient-centered care promote the integrality of care?
The incorporation of curricular changes and in the training processes towards promoting a new theoretical orientation and health practices.	The education and training of the health professionals are still predominantly from a biomedical perspective (DNV/GL, 2013, p.126). The social changes resulting from the process of demographic and epidemiological transition modify the demands and needs of the population.	Considering the aging population and the prevalence of chronic health conditions, what kind of disciplines could be incorporated into the curricula? What new demands and responsibilities are imposed on academia?
Patient-centered care for the production of safe care.	High incidence of adverse events in Brazil. The involvement of patients and their families in the care of their health contributes to a safer treatment. Concern of health systems with the issue of quality of care and patient safety.	To what extent does the legitimacy of the patient and companions in the care process contribute to safe care? How can patient and companions be involved in the healthcare process to make it safer?
Creation of specific measurement tools aimed at studies of the elements that underlie patient-centered care.	Tools for measuring patient-centered care components are used with greater emphasis in developed countries. In Brazil has no recognized, validated tool for measuring patient-centered care.	To what extent can the creation and validation of a patient-centered measurement of care measure contribute to improving the quality of care?
Development of empirical work on person-centered care in Brazil.	The development of empirical studies in Brazil that recognize patient-centered care as a realm of the quality of health services is still insufficient.	Are the perceptions about patient-centered care existing in the Brazilian health context different from those observed in developed countries? Considering the different perspectives of patient-centered care, how do we encourage the development of empirical studies in Brazil focused on this topic? Are there any particularly relevant issues?

The person/patient-centered care concept

Considering the diversity of terms that express the centrality of healthcare in the subject, the participants were shown two options that are more appropriate in health services: patient-centered care and person-centered care. The preselection of these expressions was based on the fact that the word "patient" is still widely used in the context of healthcare, and "person" is more comprehensive and has many advocates in the national and international literature.

Chart 3. Consolidated final result of discussions: Agenda proposed by the panel.

Patient-centered care recommendations			
Item	**Justification**	**Main questions**	**Main points raised**
The "person/ patient-centered care" concept	Concepts facilitate communication between individuals.	What defines the concept of patient-centered care (PCC) for the Brazilian reality?	We chose to use the term "person-centered care". It was emphasized, however, that the choice of word can be conditioned to the level of complexity in which care is provided and, in this regard, the need for caution was emphasized to avoid distortions, obscurity and loss of healthcare's primary focus. There was no precise definition of person-centered care, with the proposal to set a specific agenda for this discussion.
Contextual aspects relevant to the implementation of person/ patient-centered care.	Recognition that contextual factors, at different levels, influence the success (or not) of actions.	What are the contextual aspects that facilitate or hinder a patient-centered healthcare provision culture?	The recognition of contextual aspects is essential when you want to promote change. Context variations influence health practices, affecting their effectiveness. Contextual aspects are characterized by organizational practices such as teamwork, as well as anything in the practice environment that may hinder or facilitate the implementation of person / patient-centered care.
Policy strategies for implementation of person-centered care.	Although there are policies that consider elements of person-centered care in its composition and definition of its strategies, there is still no health policy focused on person-centered care in the country.	Should a policy be established in this regard? Which strategies would be appropriate? What are the similarities and differences between NHP and person-centered care?	We cannot deny the existence of interfaces between person-centered care and the National Humanization Policy (NHP), but we recognize that they are not the same thing. The contribution of person-centered care to safe care was highlighted. We propose that an attempt be made to establish a dialogue between groups that work in the area of healthcare quality and the group that participates in the formulation of the NHP.
Communication between health professionals and patients.	All relationships built between professionals, patients and families are permeated by communication and organizational aspects that interfere with the continuity of treatment.	What are the challenges for developing communication skills? What is the role of technologies in the communication in health services? How do we promote better communication among health professionals and between professionals and patients to foster person-centered care?	Organizational elements and lack of communication skills are aspects that can interfere with the communication process. Among the outstanding organizational factors: consultation time; the medical consultation environment; the role of technologies in the organization of care; the reduction of hierarchy gradients in the relationships among professionals; information sharing; the creation of means to enable the acquisition of accurate and reliable information; increased health literacy. Effective communication contributes to information sharing.

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Chart 3. Consolidated final result of discussions: Agenda proposed by the panel.

Patient-centered care recommendations			
Item	**Justification**	**Main questions**	**Main points raised**
Sharing information and decisions as an element of person-centered care	There are significant challenges for decision-making to be a frequent practice in health services.	What limits are essential, from the patient's point of view, for the sharing of decisions?	Communication is an essential element for sharing decisions. Privacy has been cited as a principle that must be respected and preserved. The declaration of patient's rights was pointed out as a document that should be made available in the health services. Trust influences the sharing of decisions. Media-driven news feeds the "culture of fear" and interfere with trust building.
Contextual aspects that interfere in the continuity of care and adherence to the therapeutic plan			The proposed dismemberment of this item follows: "continuity of care" was referred to as a realm of the health system; "adherence" was related to aspects inherent to the subject of care, but that does not neglect the organizational aspects.
The relationship of the principle of integrality with the patient-centered care model.			It was recommended to withdraw this item, since, "integrality" is a multidimensional concept that should not be discussed in isolation. The need for a framework to address integrality was considered. Integrality was highlighted as the essence of person-centered care.
The incorporation of changes into the curricula and formation processes towards a new theoretical orientation and health practices.	The education and training of the health professionals are still predominantly dominated by the biomedical perspective (DNV / GL, 2013, p.126), but the social changes resulting from the process of demographic and epidemiological transition modify the demands and needs of the population.	Considering the aging population and the prevalence of chronic health conditions, what kind of disciplines could be incorporated into the curricula? What new demands and responsibilities are imposed on academia?	The influence of the market on the training of health professionals. The State as an inducer of changes in the care process. The inclusion of theoretical-practical disciplines focused on the development of empathy and compassion. Interdisciplinarity and teamwork are essential elements to be encouraged during the training process.
		Are the perceptions about patient-centered care in the Brazilian health context different from those observed in developed countries? How do we encourage the development of empirical studies in Brazil focused on this theme? Are there any particularly relevant issues?	Emphasis was placed on the lack of empirical work in Brazil on the quality of health services in general, emphasizing, in particular, the need for governmental and financial support to develop research on person-centered care. It was pointed out that there are few studies in Brazil on person/patient-centered care and those that exist have generic denominations and study in isolation the theoretical elements of this practice of care.

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Chart 3. Consolidated final result of discussions: Agenda proposed by the panel.

Patient-centered care recommendations			
Item	**Justification**	**Main questions**	**Main points raised**
Development of empirical work in Brazil on person-centered care	The development of empirical work in Brazil on person/ patient-centered care that recognizes it as realm of the quality of the health services is still insufficient.	Are the perceptions about person/patient-centered care in the Brazilian health context different from those observed in developed countries? Considering the different perspectives of person/ patient-centered care, how do we encourage the development of empirical work in Brazil focused on this subject? Are there any particularly relevant issues?	Emphasis was placed on the lack of empirical work in Brazil on the quality of health services in general, emphasizing, in particular, the need for governmental and financial support to develop research on person-centered care. It was pointed out that there are few studies in Brazil on person/patient-centered care and those that exist have generic denominations and study in isolation the theoretical elements of this practice of care.
Person-centered care for safe care	The high incidence of adverse events in Brazil. Evidence that the involvement of patients and their relatives in care contributes to safer care. Concern of health systems with the issue of quality of care and patient safety.	To what extent does the legitimacy of the patient and companions in the care process contribute to safe care? How can patient and companions be involved in the healthcare process to make it safer?	The legitimation of the patient and companions in the care process contributes to a great extent for safe care. Sharing information is essential for safer care.
Creation of specific measurement tools aimed at the study of elements of person-centered care.	Tools for measuring components of person/patient-centered care are used, with greater emphasis on developed countries. It is an area where Brazil needs to move forward, validating existing tools or proposing new ones.	What realms and aspects should be considered in the measurement of person-centered care. To what extent can the proposition or validation of tools for measuring the person/patient-centered care contribute to the improvement of the quality of care?	The possibility of adapting international tools used to measure elements of patient-centered care or even the free creation consistent with the culture of healthcare in Brazil was highlighted.
Development of empirical studies on patient/ person-centered care in Brazil.	The development of empirical work in Brazil on the person/ patient- centered care that recognizes it as a realm of the quality of health services is still insufficient.	Are the perceptions about patient-centered care in the Brazilian health context different from those observed in developed countries? How do we encourage the development of empirical work in Brazil focused on this theme?	Emphasis was placed on the lack of empirical work in Brazil on the quality of health services in general, emphasizing, in particular, the need for governmental and financial support to develop research on patient/person-centered care. It was pointed out that there are few studies in Brazil on patient/person-centered care and those that exist have generic denominations and study in isolation the theoretical elements of this practice of care.

By accepting specificities and overlapping of the submitted words, the panel concluded that the use of the expression "person-centered care" would be more congruent to the reality of the

Brazilian health system. According to the opinions, the word "patient" restricts the subject's approach and suggests a specific vulnerability of the one receiving healthcare, besides excluding the health promotion component.

However, attention was also paid to the need for caution in stating that the term "person-centered care" is more appropriate than "patient-centered care" to avoid distortions and loss of healthcare's primary focus.

Patient/person-centered care relevant implementation contextual aspects

According to the panel, the organizational characteristics, determined by the way health actions and services are organized within the system, directly affect the operationalization of health practices. Thus, it can be said that public policies, the organization of the work process, the availability of resources, organizational values, leadership and the individual values of each person influence the way an institution plans and implements its activities.

Patient/person-centered care implementation strategies

Although the importance of patient-centered care for the improvement of the quality of health services is admitted, it is clear that Brazil lacks a policy that integrates all the theoretical elements and principles necessary for the establishment of this practice of care. According to the participants, some interfaces between components of patient-centered care and the National Humanization Policy (NHP) are noted, but the latter does not work with the concept in its entirety.

Assuming that, in the Brazilian context, the NHP emerged as a cross-cutting strategy for the production and reorganization of collective practices of care and management, a dialogue was proposed between quality of healthcare studies scholars and professionals who participated in the formulation and implementation of this policy to compare aspects included by the NHP with elements of patient-centered care. Such an exercise will provide favorable circumstances for the application of the patient-centered care practice, from the identification of common or divergent elements between the two.

Communication between health professionals and patients

Communication was recognized as a fundamental element and a skill to be developed in the delivery of healthcare, highlighting its complexity and dynamic character. Several factors may interfere with the quality of communication among health professionals and between professionals and patients, ranging from individual characteristics of subjects to contextual circumstances. In this context, among other aspects, important are the organizational situations – work process flow, overload of professionals; adequate infrastructure for preserving privacy; the hierarchical level of professional relationships and asymmetrical knowledge.

The panelists stated that the asymmetry of information manifested in the relationships between health professionals and patients could be attenuated by communication techniques capable of promoting a better understanding of the patient about their health condition.

The Internet was questioned, being considered a useful tool, capable of clarifying issues, but also dangerous when showing information, sometimes not very understandable, with implications for patient safety.

Shared decision-making and patient/person-centered care

Effective communication and shared decision-making are inseparable for the practice of patient-centered care. Encouraging the participation of patients and family members in care actions cooperates towards joint responsibility vis-à-vis the patient's care and safety, depending on the degree of knowledge asymmetry between health professionals and patients.

Effective communication between professionals and patients and the use of strategies that support patients in their health decisions would favor the building and strengthening of bonds and trust.

However, trust during healthcare provision is threatened by reports released by the media that highlight adverse and sensationalist events are resulting from healthcare, disseminating feelings of uncertainty and distrust in the social environment and contributing to the emergence of the "culture of fear."

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Contextual aspects that interfere with continuity of care and adherence to treatment

Given the definition of the terms "continuity of care" and "adherence to treatment", the panel suggested a disaggregated and particularized debate, reinforcing the idea of complementarity between the two, but not excluding particular characteristics in the debate of each term. According to experts, "continuity of care" depends on how healthcare and services are physically organized within the system. On the other hand, "adherence to care" reflects objective and subjective aspects concerning individuals.

The relationship between the principle of integrality and patient/person-centered care

According to experts, a specific discussion on integrality would not fit the purposes of the panel without previously referring this topic to a concept that guided the debate. Integrality cannot be guaranteed exclusively by the practice of patient-centered care; the implementation of the elements that underpin this practice contributes to comprehensive care.

The incorporation of patient/person-centered care into technical and university training

The need to include disciplines and pedagogical approaches that discuss, guide and reflect on conducts and behaviors among the subjects was recognized, showing strategies capable of improving interpersonal relationships and transform care practices.

The influence of the private sector on the higher education of health professionals in Brazil, contributing to the predominance of market logic to the detriment of social practices and repercussions on healthcare production were the core of this debate. It is socially vital to rethink the training of health professionals to facilitate their insertion in the health systems, in a more interactive and less socially fragmented way.

Patient-centered care for safe care production

The legitimization of the participation of patients and their relatives/companions in the planning and implementation of healthcare was voiced as a strategy for incident prevention. According to experts, patient-centered care and safety are connected and complementary realms of quality. Thus, strategies to promote effective communication among health professionals and with patients/caregivers; the involvement of patients and companions in the care processes, and the provision of scientific evidence to support decision-making are needed.

Formulation or adaptation of patient/person-centered care measurement tools

According to experts, the use of patient-centered measurement tools appropriate to the Brazilian health context is capable of indicating the actual implementation of this practice in the production of healthcare. It would underpin a reorganization of health practices to make them more patient-centered. Recognizing the importance of this care practice to improve the quality of health services, we considered that it would be possible to adapt measurement tools already used in developed countries to the Brazilian context or to develop tools that are more attuned to the care culture of our nation.

Empirical work in Brazil on patient/person-centered care

The number of empirical studies in Brazil focused on the area of quality of healthcare, in general, is still insufficient. Emphasis was placed on encouraging the development of studies in this area, aiming at the possible reorganization of health practices to make them more patient-centered.

Discussion

The panel's results were aligned with the literature regarding the various terminologies used to refer to the centrality of healthcare, admitting that there are particular nuances and attributes despite their interchangeability. The peculiar connotations depend on how care practices are implemented and the context in which care production occurs[4], considering that the contextual aspects determine variations in health practices, and it is fundamental to consider their role in interventions to improve the quality of care and patient safety[9].

The context of the Brazilian reality is complex and encompasses the available conditions and resources, and the availability of patient-centered care studies. Even in the context of a country such as Sweden, challenges were identified for

the practice of patient-centered care: low incentive to patient participation; the prioritization of objective aspects to the detriment of subjective elements; conflicts of power in professional relationships; inadequate infrastructure of health services; professionals who believe they already implement patient-centered practices; cultural diversity; and lack of healthcare records[10].

It is central to identify strategies for patient and caregiver involvement towards reducing the avoidable harm produced by health services[8,11], considering patient-centered care and patient safety as complementary and inseparable realms of quality.

Sharing decisions among health professionals, patients and companions was stated by panelists as a necessary skill in implementing patient-centered care. Studies show that clinical outcomes are more effective[11,12] when the patient is involved in the decisions regarding his treatment. However, sharing decisions in the health practice requires from professionals involved ethical responsibilities, given the asymmetric technical knowledge in the relationship with the patient. It is crucial for health professionals to show evidence and scientific uncertainties about treatment alternatives[12] clearly.

The idea that communication is a strategic element for quality healthcare has permeated several points of discussion in the panel, pointing out that its effectiveness favors shared decisions, the co-production of health services, increased patient safety, influencing the clinical results[12,13] positively. Effective communication is one that improves the quality of healthcare[14]. But although communication is recognized as an essential tool, it still faces challenges in the physical and relational spheres. According to panelists, it is vital to create favorable conditions and improvement projects that can make communication effective and thus promote patient-centered care.

The quality of vocational training was raised as an issue that needs to be questioned, rethought, and perhaps reformulated. Some educational institutions have been implementing curricular changes in their training courses, incorporating disciplines that provide reflections on health practices[15]. However, in general terms, knowledge fragmentation, growing specialization and technological valuations still prevail, with a predominance of the biological vision to the detriment of the social vision[15].

It would be appropriate to establish situations favorable to the promotion of individual and organizational changes that facilitate the incorporation of patient-centered care as one of the objectives of the quality of care in the Brazilian health services.

In short, the experience reported here has allowed the aggregation of several views and perspectives on the person/patient-centered care and its underpinning theoretical elements. It contributed to the proposal of research bases that will allow an in-depth analysis on the person/patient-centered care, with potential aggregation of scientific evidence on paths towards its implementation and evaluation of effectiveness in the Brazilian health context.

Colaboradores

JLSQ Rodrigues worked on the bibliographic research about the topic, writing, and event organization, consolidation and analysis of the discussion results. MC Portela was important regarding methodology guidance, event organization, final writing revision and indication of the experts that composed the panel. AM Malik participated as a member of the expert panel that was elaborated in the National School of Public Health (ENSP) for discussion on the topic patient-centered care; also worked in the final revision of the submitted material, adding pertinent considerations on the discussed topic.

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