

FACILITATORS AND BARRIERS OF PATIENT INVOLVEMENT IN HOSPITAL SERVICES: INTEGRATIVE REVIEW

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ABSTRACT

Objective: to identify the facilitating factors and barriers that influence patient involvement in hospital services. **Method:** integrative review; search of articles published between January 2011 and December 2020, in the electronic databases PubMed, Web of Science, Cinahl, Lilacs and Scopus, using descriptors related to "patient involvement", Barriers, Facilitators, in English, Spanish and Portuguese. Data collection was performed from May to June 2021, identifying 32 publications that met the inclusion criteria.

Results: the analysis resulted in three categories of facilitating factors and barriers: communication, actors of involvement and organizational culture, allowing the elaboration of a theoretical model of patient involvement. This model shows that in the centrality of the process are the actors involved, that is, patients and professionals, inserted in an organizational context, being influenced by leadership, culture, environment, available resources and processes, where communication permeates as a basis for involvement.

Conclusion: the facilitating factors and barriers identified in this review, synthesized in a theoretical model, allow transcending theoretical knowledge for practice. The complexity to operationalize this model requires patients, professionals, health services and society join forces to make this theoretical proposition a practice incorporated by the services.

DESCRIPTORS: Patient experience. Involvement. Facilitators. Barriers. Health services.

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FACILITADORES E BARREIRAS DO ENVOLVIMENTO DO PACIENTE NOS SERVICOS HOSPITALARES: REVISÃO INTEGRATIVA

RESUMO

Objetivo: identificar os fatores facilitadores e as barreiras que influenciam no envolvimento do paciente nos serviços hospitalares.

Método: revisão integrativa; realizada busca de artigos publicados entre janeiro de 2011 e dezembro de 2020, nas bases eletrônicas PubMed, *Web of Science*, Cinahl, Lilacs e Scopus, utilizando descritores relacionados a *"patient involvement"*, *Barriers, Facilitators*, nos idiomas inglês, espanhol e português. Coleta de dados realizada de maio a junho de 2021, identificando-se 32 publicações que atenderam aos critérios de inclusão. **Resultados:** a análise resultou em três categorias de fatores facilitadores e barreiras: comunicação, atores do envolvimento e cultura organizacional, permitindo a elaboração de um modelo teórico de envolvimento do paciente. Esse modelo mostra que na centralidade do processo estão os atores envolvidos, ou seja, pacientes e profissionais, inseridos em um contexto organizacional, sendo influenciados pela liderança, cultura, ambiente, recursos disponíveis e processos, onde a comunicação perpassa como base para o envolvimento.

Conclusão: os fatores facilitadores e as barreiras identificadas nesta revisão, sintetizados num modelo teórico, permitem transcender o conhecimento teórico para a prática. A complexidade para operacionalizar esse modelo requer que pacientes, profissionais, serviços de saúde e sociedade unam os esforços para tornar esta proposição teórica em uma prática incorporada pelos serviços.

DESCRITORES: Experiência do paciente. Envolvimento. Facilitadores. Barreiras. Serviços de saúde.

FACILITADORES Y BARRERAS PARA LA PARTICIPACIÓN DEL PACIENTE EN LOS SERVICIOS HOSPITALARIOS: REVISIÓN INTEGRATIVA

RESUMEN

Objetivo: incidir en los factores y barreras de la implicación del paciente en los servicios hospitalarios.

Método: revisión integradora; búsqueda de artículos publicados entre enero de 2011 y diciembre de 2020, en las bases de datos electrónicas PubMed, Web of Science, Cinahl, Lilacs y Scopus, utilizando descriptores relacionados con "involucramiento del paciente", Barreras, Facilitadores, en inglés, español y portugués. La recolección de datos se realizó de mayo a junio de 2021, identificándose 32 publicaciones que cumplieron con los criterios de inclusión.

Resultados: el análisis resultó en las tres categorías de facilitadores y barreras: comunicación, factores de involucramiento y cultura organizacional, permitiendo la elaboración de un modelo teórico de involucramiento. Este modelo muestra que en la centralidad del proceso están los actores involucrados, es decir, pacientes y profesionales, insertos en un contexto organizacional, siendo influenciados por el liderazgo, la cultura, el ambiente, los recursos disponibles y los procesos, donde la comunicación permea como base para el involucramiento.

Conclusión: los factores y barreras identificados en esta revisión sintetizados en un modelo teórico, permiten trascender el conocimiento teórico para la práctica. La complejidad para operacionalizar este modelo requiere que los pacientes, los profesionales, los servicios de salud y la sociedad se unan para hacer de esta propuesta teórica una práctica incorporada por los servicios.

DESCRIPTORES: Experiencia del paciente. Intervención Facilitadores. Barreras. Servicios de salud.

INTRODUCTION

Health organizations establish policies and strategies that promote the direct involvement of patients and families in their own care, but not necessarily in the development and improvement of the services they use. Involvement in the reformulation of services is an alternative to design processes that meet their needs and achieve better health outcomes¹. In addition to organizational policies, flexible work processes are important as they provide different ways for the user to engage in their own care^{1–2}. Such involvement has increasingly conquered the recognition as a care component of health care technologies³.

The concept of patient involvement has been increasingly used by professionals and, therefore, its meaning needs to better clarified. Upon reading the literature, shared decision-making, assisted decision-making, patient engagement^{4–7} were found as synonyms. Engagement is understood as the individual's ability to choose and actively participate in their own care according to their reality, in a process of cooperation between patients, professionals and health institutions, aiming to improve the care experiences⁸. Seeking to deepen understanding, one comes across the idea of co-production, being understood in health as the sharing of information and decision-making between users and professionals of the service^{9–10}. Involvement has contributed to the reduction of the occurrence of adverse events¹¹, lower costs¹², shared decision-making¹³ and in patients acting as co-producers for safe care¹⁴.

On the premise of involving patients, the "Montreal Model" is based on collaboration and partnership between patients, researchers, professionals and health managers. Patients act as consultants for health improvement, participating in the development of public policies¹⁵. In the United States there is a movement that suggests the participation of patients and their representatives in governance boards. This participation can increase user confidence in health services, in addition to improving transparency and awareness of the importance of the patient's voice¹⁶.

In Brazil, user involvement is one of the axes of the National Patient Safety Program (PNSP), and is considered as one of the most complex, as it involves changing the culture not only of professionals, but also of users of the health service¹⁷. Despite being a challenge for the Brazilian context, some hospitals already have initiatives aimed at humanized care, educational actions and the change to a user-centered organizational culture^{18–20}.

The positioning of the patient at the center of the health care process, when considering the hospital scenario in Brazil, still seems to be very distant. Encouraging the patient to participate in care, decision-making and even planning improvements in services seems to configure a utopian context, almost unattainable. In order to transcend this utopia in reality, it is important to take into account the facilitating factors, strategies and barriers of patient involvement in the clinical practice of health organizations, envisioning the development of current initiatives^{21–22}.

Identifying the perceived barriers in other studies can help in the construction of strategies for patient involvement in the place of professional practice. Similarly, by knowing the factors that facilitate them, one can use them as elements that prepare the context for the new approach. This knowledge will certainly contribute to reduce the gap between policies, programs and practices related to patient involvement in their care.

The study is relevant, as the search for understanding this theme, based on scientific evidence, highlights strategies for hospital services, making it possible to transcend theoretical knowledge for care practice through scientific knowledge.

Thus, the present study has a guiding question: what are the facilitating factors and barriers that influence the involvement of adult patients in hospital services? In search of an answer to this question, the following objective was elaborated: To identify the facilitating factors and barriers that influence patient involvement in hospital services.

METHOD

An integrative literature review with five stages: elaboration of the research question, search in the literature search, evaluation of studies, data analysis and presentation of the review²³.

The searches were carried out from May to June 2021, in the electronic databases PubMed, Web of Science, Scopus, LILACS and CINAHL, using the descriptors "involvement patient", "patient engagement" Factors, Factor, Barrier, Barriers, Facilitator, Facilitators, Difficulty, Impediment, "health service", "health services", healthcare. The search strategy used was: (("patient involvement" OR "patient engagement") AND (Factors OR Factor OR Barrier OR Barriers OR Facilitator OR Facilitators OR Difficulty OR Impediment) AND ("health service" OR "health services" OR healthcare)).

The selected studies were published between January 2011 and December 2020 in the English, Spanish and Portuguese languages. Articles from primary studies, with abstract and texts available in full were included for analysis.

Exclusion criteria were: scoping review, integrative review, systematic review, books, documents, editorial notes, conference summaries and study protocols. After reading the abstracts, articles with emphasis on pediatric patients, studies with patients of specific pathologies, performed in primary and outpatient care were excluded, because it is believed that the patient's involvement in their care occurs differently in these scenarios.

Initially, the titles of the articles were read independently by two reviewers during the selection phase. The reviewers then read the abstracts. The publications that met the eligibility criteria and had the consensus of the two reviewers were selected for full reading.

The full reading of the texts was performed by three reviewers, and the selections were compared in order to evaluate the compatibility of the findings and discuss divergences, and then to decide the inclusion or exclusion of the article in the review. A data collection instrument was developed with the following items: title, authors, year of publication, journal, country in which the research was carried out, study objective, methodological design, evaluation of the quality of the study regarding methodological rigor and main results related to barriers and factors facilitating patient involvement. The results regarding barriers and facilitators were analyzed for their content, and themes were identified and grouped into categories.

In phase 4, which comprised the critical analysis of the included studies, the articles were evaluated for the quality of methodological rigor, using the 2018 version of the Mixed Methods Appraisal Tool (MMAT) instrument, as it allows the evaluation of methodological quality in five categories of studies. As suggested in the tool itself, the articles were classified between 1 and 5 asterisks (*), where each asterisk represents that the article contains the evaluated criterion. In this sense, articles classified as ******(5) are those with the best quality²⁴. The recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) were followed for the preparation of this article.

RESULTS

During the database search, the search terms compiled 1,436 articles. Thirty-six articles were discarded due to being included in more than one database. The reading of the titles resulted in 225 articles being selected for the reading of the abstracts. After reading the abstracts, it was identified that 61 were eligible for reading the full. From the full reading, 29 articles were excluded; systematic review (n=1), pediatric population (n=1), specific pathologies (n=9), primary care, outpatient clinic or nursing home (n=9) and without information on barriers or facilitating factors (n=9). Thus, the present review is composed of a sample of 32 articles, which included the inclusion criteria, relating to the research question and the objective that is intended to be achieved with this study (Figure 1).

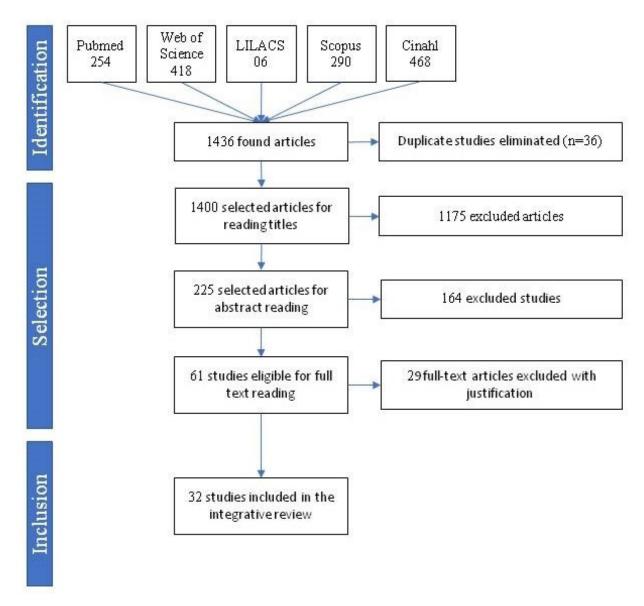


Figure 1 - Flowchart of the selection phases of the articles for review, according to the PRISMA recommendation. Porto Alegre, RS, Brazil, 2021.

The procedures for searching for articles covered the last decade of publications (2020-2011) existing in the five databases previously selected. The period of the last five years was the most fruitful, totalling 29 publications. No articles were found in the years 2015 and 2012. The studies were conducted in the following countries: United States of America (n=6), Australia (n=6), Sweden (n=5), United Kingdom (n=3), France (n=2), Netherlands (2) and others (n=8).

Regarding the method, 19 studies with a qualitative approach were found, 11 with quantitative approach and two studies of mixed methods. The methodological rigor of the publications was predominantly between 5* and 4*, indicating high-quality studies.

The analysis of the results allowed the construction of three categories: "Patient involvement: focus, communication. What do we need to know?", "The actors of involvement: patients and professionals" and "Organizational culture and work environment: Repercussions for patient involvement". Facilitating factors and barriers to patient involvement are described throughout each category.

Patient involvement: in focus, communication. What do we need to know?

The categorization of the results of the studies revealed communication as one of the central elements that permeates the patient's involvement process. A prominent position is given to it from the various citations it received in the analysed studies, which may contribute or hinder involvement. Communication for patient involvement with their care was emphasized in clear communication between professionals and patients^{25–29}. Simple language is highlighted, and no medical terms are used³⁰. "Enhanced communication"³¹ is an expression used to qualify communication for engagement. These findings reveal that, for the process to occur successfully, it is necessary, in addition to clear communication, the combination of oral and written information^{32–35}, because it allows patients to consult the information several times³², suggesting the use of informative folders³³ and giving special attention to the "written" at the time of hospital discharge³⁵.

Clear communication also paves the way for the adequate interaction between professionals and patients, and it is highlighted that patients feel comfortable asking physicians for explanations and information is recognized as sufficient³⁴ and "understandable,"³⁵ characterized by continuous dialogue between clinicians and patients³⁶. Establishing good communication with professionals, based on respect and dignity^{37–38}, in attentive and friendly treatment³⁸, patients feel valued²⁸ and encouraged to share their point of view^{25,27}, express their opinions²⁵ and ask questions^{25,30}. Thus, an environment for shared decision-making is established¹³, with patient participation in important decisions²⁵, in other words, care is shared²⁶.

When considering the relationship between professionals and patients, another attribute that stands out is the ability of professionals to successfully commence the communication process, demonstrated by the findings that explain the oral communication skills of professionals²¹ and the communication capacity of professionals³⁸. Some key moments provide information, such as upon hospital admission and at the time of test results³². It is understood that when professionals focus on more appropriate moments for information exchange, with clear communication and active listening, this can favor a relationship of trust between professionals and patients, which was mentioned in some studies^{27–28,30}.

Communication is identified as a resource with great potential to improve patient involvement, but it has also been identified as a barrier in the process, when it is perceived that physicians use words that patients do not understand³⁴, the team does not have the ability to communicate effectively³⁸, there is information overload at hospital discharge and patients and health staff speak different languages³³ and there is no interpreter available³⁸. Thus, communication can also be fragile⁵ and prone to flaws^{5,34}. The complexity of this important element of human interactions warns of the existence of communication challenges⁶.

Flawed communication may be connected to the conflicting relationships of patients and professionals, resulting in hostile and rude behaviour on the part of professionals³⁸ and an offensive posture of the patient and family³⁰. Difficulties in the relationship between patients and professionals³⁰ may be associated with the fact that it considers information to be unidirectional³³ and to the existence of conflicting information among professionals³⁷. The divergence of information among professional's results in insecurity for patients³². It is also true that the patient, when feeling powerless to share decision-making, lets the team decide²⁶. Professionals warn that tensions may arise during negotiation with patients about cooperation and autonomy³⁹.

The actors of engagement: patients and professionals

Continuing the understanding of facilitating factors and barriers to patient involvement, it is evident that aspects of the individuals present in the care process - patients and professionals - are of

renowned importance. In this perspective, they include the following themes: patient health conditions, sociodemographic and cultural characteristics and their health literacy, motivation for engagement, patient safety, professional preparation, as well as the feelings mobilized in them.

The patient's health conditions, sociodemographic and cultural characteristics and their knowledge about the health/disease process, also known as health literacy, have elements that facilitate involvement. Thus, the state of health (level of anxiety, depression)⁴⁰ or a patient with a better mental health status¹³, together with knowledge about health and aspects of his disease^{41–43}, previous experiences and the ability to recognize changes in his/her clinical condition²⁹ are considered facilitating aspects in the process of care involvement. Patient involvement is greater in the face of a serious health problem³⁴. Chronic patients⁴⁰ are predisposed to involvement. Moreover, the term "specialist patients" was also mentioned and, for this, they need to have a balanced experience of the disease and knowledge²¹.

On the other hand, the patient's health conditions³⁵ may compromise their participation, constituting a barrier to involvement. The elements found were: anxiety³⁶, cognitive status (dementia, cognitive impairment)^{29–30,36}, and that patients with dementia or confusion present particular challenges for working together to achieve certain goals, such as infection prevention, as in the case of one of the studies³⁹. Corroborating this data, it was also seen that there are patients who have difficulties in with retaining information³⁵.

The patient's status (hearing, visual, cognitive, psychiatric deficit)⁴⁰ and the patient's fragile condition³³ also compromises involvement. In line with these aspects, limitations of the patient due to the disease and the fear of the occurrence of falls⁴⁴ may hinder engagement. In addition, it is presented that intensive care patients acquire a passive role⁴⁴.

Sociodemographic and cultural characteristics also play a facilitating role for involvement, such as: women have a greater capacity to establish relationships with health professionals^{41,43}, absence of economic deprivation⁴¹, people with a high level of education⁴⁵. On the other hand, the barriers mentioned in the studies were: patients from the rural population²⁸, financial responsibility (patients avoiding services to limit costs)¹³, inadequate literacy, individuals with lower schooling; disadvantaged social classes^{28,43}, elderly^{28,40,42–43} tend to be less involved, because they rely more on the team of professionals^{40,42}. The more conservative social norms, the less likely it is that people are involved in medical decision-making, and that the social context also determines this role⁴⁵.

Health literacy as well as poor knowledge can be a barrier to involvement. Studies found elements that characterize this subcategory, such as: lack of knowledge regarding health insurance³⁶, lack of knowledge of patients about their rights, about the functions of health professionals⁴⁰, low health literacy³², patients assess that they are not informed³², difficulties in understanding patients about medical issues³⁴, and patients' ignorance about how and under what circumstances to access emergency services³⁸.

The motivation for involvement configures another set of results listed in the studies, resulting from the patient³⁶, the presence of family and friends^{33–34} and the nursing team³⁵. Assertive posture of the patient and family³⁰ and information provided by family members about the patient's health/disease history³⁰ are recognized as facilitating elements for involvement. In addition, factors related to the patient such as the desire to be more involved³⁵, the adoption of a positive mentality, self-motivation, efforts to become independent and be a "good" patient, and also the motivation that comes from a personal mobilization to seek strength in religion⁴⁴.

Patient safety was a theme present in some studies, presented as a facilitating element for engagement. The references to this theme were: patient involvement can avoid errors²⁷, patient education about safety was important to improve the patient's perceptions and attitudes about their

own safety while in the hospital⁴⁶, and patients with greater clinical severity had an increase in the score regarding the perception of safety⁴⁶.

The literature demonstrates elements that act in the motivation for engagement, however, there are also those patients who present a passive attitude to engagement. In this approach, patients who consider *physicians experts* and, therefore, wait for them to be involved in decision-making³⁴, and also, those who believe they should be a "good" patient, adopting a role of passive care recipient⁴⁴. This subcategory also includes the lack of ability of patients to be involved as partners³⁹, in situations such as: difficulties in asking questions to physicians⁴¹, patients do not question professionals, because they view professionals as authorities, and fear of not receiving adequate care^{27,40,47}, reflecting the lack of patient involvement in decision making³⁷.

The studies also present the preparation of the professional as a facilitating aspect. Professionals qualified for involvement are those who have characteristics such as: adaptability, according to the needs of each patient²⁷, autonomy, skills and flexibility;⁵ encourage the patient and family member to perform a list of topics they would like to discuss; know the patient's history, question their desires and preferences;³⁰ and the pharmacist's competencies (knowledge about medications, patient listening, welcoming and calm posture)³⁵ were mentioned.

When considering these findings, and when the preparation of the professional lacks attributes, it is a barrier to engagement. Manifestations in this sense were identified in the expressions: lack of knowledge of how to involve patients and their representatives²¹, professionals do not involve patients³³, physicians do not usually ask patients for information³⁴ not valuing subjective experiences²⁹, participants relate empowerment with patient-centered care³¹.

Patient engagement is also able to mobilize feelings in professionals. When there is a good involvement, it can have repercussions on how professionals feel regarding work satisfaction⁶. On the other hand, it can also mobilize feelings that do not contribute to the process, such as: actively working, aiming at patients getting involved in their own care, can be a new source of stress²⁵, fear of being processed if they inform patients about errors⁴⁰ and nurses' fear that patients may fall, resulting in the restriction of patients' autonomy⁴⁴.

Added to these findings, are the statements that involving patients in the health team can be seen as a conflicting practice²¹ and the fact that health professionals claimed that they did not like to be reprimanded by patients, seeing their comments as negative⁴⁷. Furthermore, health professionals feel pressured by the presence of the patient or family member during the case discussion, the presence of more than one family member in the meetings³⁰, difficulties that professionals have in sharing all information with patients and family members^{29–30} characterize situations that mobilize feelings which act as barriers to the practice of involvement. Therefore, the professionals recognized that patient involvement is a key aspect, but the degree to which they were willing and able to accept an active role in patient involvement was different⁴⁸.

It is observed that there are many aspects that are interconnected, with regard to the actors of involvement, professionals and patients. By broadening the look at the factors that influence the involvement process, it is perceived that there is a repercussion of external elements, recognized here by organizational elements, emerging the third thematic category.

Organizational culture and work environment: repercussions for patient involvement

With regard to facilitating factors, one of the points most addressed by the studies was the existence of an organizational culture with emphasis on patient involvement and professional autonomy, seeking collaborative action from all stakeholders, from executive manager to bedside professionals^{28,36,48}. A shared view of patient involvement as a priority, strategic objectives focusing on improving patient-centered care, and the recognition of the institution's brand as a patient-centered service are observed^{48–49}. It is noteworthy that there are organizations that are concerned with improving employee satisfaction and that associate it with patient satisfaction, in a constant movement of development, improving the culture and work environment, on the premise of better involvement of their patients⁴⁹.

According to the selected publications, the organizational culture is routinely and intrinsically translated into the practice of patient involvement. In this sense, several authors mentioned the participation of patients in multidisciplinary meetings, organizational decisions, at the point of care delivery (e.g., partners in care, inclusion in hand-offs; bedside transfers, family access), in patient and family advisory committees, representation in the board of directors, and in quality improvement committees^{16,28,49–50}.

The systematic collection of patient feedback has been described as a facilitating factor, because it allows generating reports that are shared with the professionals who provide care, identify areas of improvement of patient-centered care, develop new solutions, and redesigning health services. Patient feedback indexes, together with other metrics, assist in employee performance assessments, and in some places are associated with compensation incentives⁴⁹.

On the other hand, the investigation points out that some of the studies analyzed demonstrated culture as a possible barrier to involvement. Situations such as the resistance of professionals to adopt good practices and the difficulty in changing the mentality of employees from a "supplier-focus" approach to a "patient-focus" approach are described as cultural issues of organizations that hinder patient involvement^{49–50}.

When the focus is related to health teams, studies show that actions related to professionals, such as depending on guidance to the health team, investing in their development, encouraging work in multidisciplinary teams, being the medical leader involved in the process and sharing information among colleagues, are pointed out as facilitators of patient involvement^{21,29,31,51}. In terms of management model, patient involvement seems to benefit from a mixed approach, where management support coexists at all organizational levels (top-down approach) and the role related to the responsibility of frontline teams (bottom-up approach)⁵¹.

The importance of the role of leaders as an attribute for patient involvement is highlighted, highlighting the performance of senior leaders⁴⁹, and also cascading leadership, acting from strategic to operational level with team integration and, mainly, stimulating patient participation in discussions^{21,30}. However, when there is the presence of hierarchy in professional groups with hegemony of medical power, rigid and formal structures in the institution, discontinuity of care (temporary professionals and high turnover of professionals), the existence of several physicians performing care, such factors make it more difficult to share decision-making and patient involvement^{5–6,27–28,40,51}.

Another point addressed by one of the studies refers to a disparity between existing options, i.e., a mismatch between what users seek and the services offered by organizations can lead to barriers to patient engagement⁵. The gap resulting from the lack of expectations of users and the service offered may justify the uncertainties regarding safety and quality of care, making it difficult to engage patients. In this sense, one of the studies reports that patients' expectations regarding the quality of services, the occurrence of adverse events, doubts about skills, knowledge and supervisory processes around junior and newly qualified physicians can be configured as barriers to patient involvement³⁸. This same study also reported that the lack of affordable care, expensive and inadequate prices of services can hinder the engagement of patients in their care³⁸. The lack of confidence in the health system²⁹ and the finding of conflict between the information given by the hospital and primary care³⁵ are also perceived as barriers.

The existence of a pleasant environment, with resources to meet the expectations of patients and their caregivers and that provides safety, are also referred to as factors that facilitate the involvement of patients in their care^{5,30,44}. On the other hand, the authors report that the lack of resources related to the hospital environment is understood as a barrier to involvement, in cases such as: the layout of physical areas and amenities^{6,44}, as well as the lack of privacy for conversations with patients and professionals (wards with many beds or lack of places to communicate with patients)^{5,27,33}. The hospital clothes used by the patients that do not favor the act of dressing, are also considered barriers⁴.

The literature shows that the time of professionals with the patient also influences the involvement, considered a facilitating factor when the professional is available. For example, it was identified that when the pharmaceutical professional has time to dedicate to the patient, he is seen as a facilitator of engagement³⁵. On the other hand, when the availability of time does not exist or is limited, it has been identified in studies as a barrier to engagement, and about 30% of the articles included are related to the time restriction and work overload faced by health professionals^{5–21,25,27,29,31,33–34,44,51}. In addition to time, the scarcity or limitation of financial resources for the creation and maintenance of projects related to patient involvement, as well as the lack of computerized and integrated data systems between health institutions of different levels of care negatively impact patient engagement^{5,21}.

In an effort to summarize the studies that comprised the sample, Figure 2 represents the three categories that emerged from the 32 studies, in a theoretical model in which, at the center of the process, the actors involved - patients and professionals - are inserted in an organizational context, being influenced by leadership, culture, environment, available resources and processes, and where communication permeates as a basis for involvement.

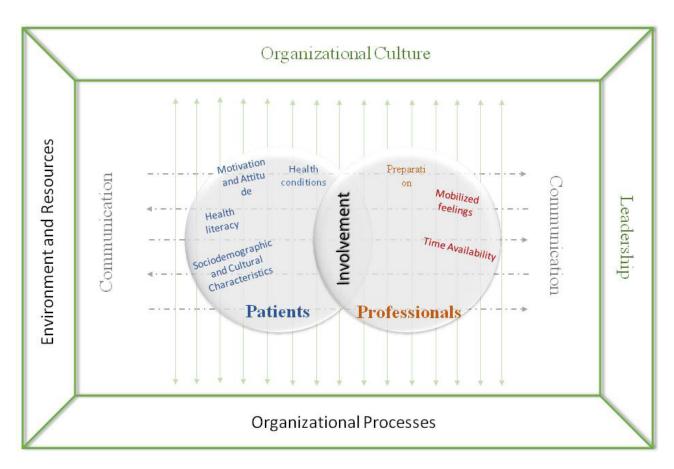


Figure 2 - Theoretical model elaborated through the synthesis of the results of the integrative review. Porto Alegre, RS, Brazil, 2021.

DISCUSSION

The research revealed that communication is highlighted regarding patient involvement. These findings are consistent with other studies, where it is demonstrated that attentive listening, together with clear communication, reflects in shared decision-making;⁵² and the continuous dialogue between professionals and patients^{53–54}, empathic and understandable communication, allocating adequate time for listening⁵⁵, are considered facilitating factors for involvement. The "Speak Up" program advocates counselling to the user through resources such as videos and informative pamphlets accessible to the lay population. These materials may encourage involvement in decision-making related to their health⁵⁶, which corroborates the results of this review that mention the importance of combining oral and written information. In addition to communication, adequate interaction between professionals and patients can act positively on the involvement process, and this interaction is based on a relationship of trust between patients and professionals^{54,57}.

Patient participation in health care has generated studies on the concept of co-production in health, highlighting its contribution to patient safety strategies implemented in hospitals¹⁴. Patients and their families, as end-customers of health services, need to be seen as partners in the planning, implementation and improvement of the care provided⁵⁸. For this, two key elements are needed: to understand the experiences, needs and expertise of patients and family members before implementing solutions, and to follow the premise "nothing about me, without me", where patients, family members and caregivers are part of the co-design team to create a range of ideas to solve problems in services that are important to them, in addition to testing and evaluating solutions⁵⁹.

In order to contribute to successful care, it is necessary that both professionals and patients be prepared to act adequately. Professional training and continuing education programs need to train the professional to work and respect the patient's centrality in the health care process. Patients, on the other hand, need to be prepared for their action through educational approaches stimulated and implemented by frontline professionals, in an effort to privilege health literacy⁶⁰. Health literacy appears to be a way to improve health outcomes. Investing in health literacy brings benefits to the health system, the patient and professionals, giving greater effectiveness and efficiency⁶¹. Education during the hospitalization process aims to encourage patients to be interested in their health, providing changes in behavior and improvements to patient safety²⁸.

In addition to education, the characteristics and behavior of professionals and patients were also reported by the analyzed studies. Regarding professionals, their satisfaction influences the quality of care provided, which is in line with the Quadruple Aim Model, which discusses improving the experience of health professionals in their work process^{62–63}. The application of this model demonstrated better involvement of employees in their work process, increasing confidence in leadership, improving patient experience scores, as well as reducing costs⁶³.

In relation to patients, it is highlighted that actively listening to what the health team has to say, as well asking questions about their health/disease process, using the Internet and reliable websites to obtain knowledge about their disease, are elements that stimulate engagement⁶⁴. It is noteworthy that patients need to be stimulated to get involved in decisions about their health⁶⁴. Patients need motivation to engage in their care and processes that require greater commitment and participation. Individuals are usually motivated by issues that are relevant to their lives and in which they will have some benefit from this participation²².

Organizational culture is widely described in the literature as an important factor that influences patient involvement, which is in line with the results of this review. In order to allow the involvement of patients and family members in hospital institutions, it is recommended that this is a fundamental

value of organizations, that care processes and incentives are adapted to promote patient-centered communication, that governance structures are shared and facilitate patient involvement at all levels of the organization⁶⁵.

Other publications also highlight the importance of the presence of leaders that allow and facilitate the transformation of organizational culture, with a strategic focus on person-centered care⁶⁶. Leaders at all levels are responsible for disseminating patient involvement throughout the institution, as well as leading improvement initiatives through professional engagement, resource allocation, development of data infrastructure and information systems, and establishing partnerships with various stakeholders⁵⁹.

Although little described by the publications included in this review, the involvement of patients and family members more specifically in the safety and quality of care has received special prominence in the literature. In Brazil, the involvement of patients in the safety of care is contemplated in the National Plan for Patient Safety published in 2013¹⁷. More recently, the World Health Organization, in the Global Action Plan for Patient Safety 2021-2030, highlights the importance of patient involvement and notes that "patient involvement and empowerment is perhaps the most powerful tool in improving patient safety."

Limitations and strengths

Regarding the limitations of the study, only studies conducted in hospital services were included in the search and no patient with specific pathologies was invited, as it is understood that the patient's involvement for their care occurs differently in these scenarios and in certain groups. Another limitation is that the grey literature has not been explored.

As for strengths, it is understood that the evaluation of the quality of the published articles was included, as well as the analysis of the results by three reviewers, ensuring scientific rigor in order to avoid the occurrence of interpretation bias, in an effort to analyze the results of the study together. Another strength is the large number of articles that addressed the research object, which corroborates one of the fundamental aspects to be evaluated by the researcher, which is the sample size, emphasizing the importance of an exhaustive literature search⁶⁷. The integrative review presents the state of the art on the subject. At the same time, there is the benefit of knowing the main experts who are publishing research results⁶⁸, providing support for the transfer of knowledge to clinical practice, and reducing the gap between knowledge and practice⁶⁹.

CONCLUSION

The results reveal that patient involvement is a multifactorial theme as several elements are present and interact simultaneously so that the hospitalization experience may configure the involvement. The elements originate at the various organizational levels and cover different actors that make up the hospital service scenario, giving greater complexity to the - apparently simple - theoretical strategy of involving the patient with their care and the quality of care.

The differential of this study was the creation of a theoretical model of patient involvement, which can serve as a pillar to guide hospital services on this theme. It is understood that the model presented can be adapted to each service and reality, considering the specificities of the different scenarios, and thus assist professionals, patients and health services in this process of involvement.

The complexity of the operationalization of this model requires that patients, professionals, health services and society join forces to make this theoretical proposition a practice incorporated by the services.

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NOTES

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Writing and/or critical review of the content: Souza ADZ, Hoffmeister LV, Moura GMSS.

Review and final approval of the final version: Moura GMSS.

APPROVAL OF ETHICS COMMITTEE IN RESEARCH

Approved by the Ethics Committee in Research with Human Beings of the *Hospital de Clínicas de Porto Alegre*, *Universidade Federal do Rio Grande do Sul*, opinion no.4,929,033, CAAE: 49110921.5.0000.5327.

CONFLICT OF INTEREST

There are no conflicts of interest.

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