







STRATEGIES FOR INVOLVING PATIENTS AND CAREGIVERS IN PATIENT SAFETY ACTIONS: INTEGRATIVE REVIEW

ESTRATÉGIAS DE ENVOLVIMENTO DOS PACIENTES E ACOMPANHANTES NAS AÇÕES DE SEGURANÇA DO PACIENTE: REVISÃO INTEGRATIVA

ESTRATEGIAS PARA INVOLUCRAR A LOS PACIENTES Y ACOMPAÑANTES EN LAS ACCIONES DE SEGURIDAD DEL PACIENTE: REVISIÓN INTEGRATIVA

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ABSTRACT

Objective: to describe the evidence available in the literature on the strategies for involving patients and caregivers in actions to promote patient safety in hospital units. **Method:** integrative literature review in PubMed, CINAHL, Web of Science, Scopus, and Cochrane databases between 2005 and 2020. **Results:** nine articles were selected in the final sample, which recommended the standardization of communication, technological resources, videos, leaflets, games, dialogued interviews, questionnaires, and booklets as strategies for involving patients and caregivers. The studies highlighted the importance of knowing the profile of participants to choose strategies considering the potential and limitations of each intervention. **Conclusions:** it was found that, despite the scarcity of studies with high evidence, the articles found present important strategies for strengthening the practices of inclusion of the patient and caregivers in patient safety, in addition to motivating the realization of new productions on this theme.

Keywords: Patient Safety; Evidence-Based Practice; Family; Nursing; Patient Preference.

RESUMO

Objetivo: descrever as evidências disponíveis na literatura sobre as estratégias de envolvimento dos pacientes e acompanhantes em ações de promoção da segurança do paciente em unidades hospitalares. **Método:** revisão integrativa da literatura nas bases de dados PubMed, CINAHL, Web of Science, Scopus e Cochrane entre 2005 e 2020. **Resultados:** foram selecionados nove artigos na amostra final, os quais recomendaram a padronização de comunicação, recursos tecnológicos, vídeos, folhetos, jogos, entrevistas dialogadas, questionários e cartilhas como estratégias de envolvimento dos pacientes e acompanhantes. Os estudos ressaltaram a importância de se conhecer o perfil dos participantes para escolha das estratégias considerando as potencialidades e limitações de cada intervenção. **Conclusões:** constatou-se que, apesar da escassez de estudos com altas evidências, os artigos encontrados apresentam estratégias importantes para o fortalecimento das práticas de inclusão do paciente e dos acompanhantes na segurança do paciente, além de motivar a realização de novas produções nessa temática.

Palavras-Chave: Segurança do Paciente; Prática Clínica Baseada em Evidências; Família; Enfermagem; Preferência do Paciente.

RESUMEN

Objetivo: describir la evidencia disponible en la literatura sobre las estrategias para involucrar a pacientes y cuidadores en acciones de promoción de la seguridad del paciente en las unidades hospitalarias. **Método:** revisión integrativa de la literatura en las bases de datos PubMed, CINAHL, Web of Science, Scopus y Cochrane entre 2005 y 2020. **Resultados:** se seleccionaron nueve artículos en la muestra final, los cuales recomendaban la estandarización de la comunicación, recursos tecnológicos, videos, folletos, juegos, entrevistas dialogadas, cuestionarios y folletos como estrategias para involucrar a pacientes y cuidadores. Los estudios destacaron la importancia de conocer el perfil de los participantes para elegir estrategias considerando el potencial y las limitaciones de cada intervención. **Conclusiones:** se encontró que, a pesar de la escasez de estudios con alta evidencia, los artículos encontrados presentan estrategias importantes para fortalecer las prácticas de inclusión de pacientes y acompañantes en la seguridad del paciente, además de motivar la realización de nuevas producciones sobre este tema.

Palabras clave: Seguridad del Paciente; Práctica Clínica Basada en la Evidencia; Familia; Enfermería; Prioridad del Paciente.

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INTRODUCTION

The term patient safety is understood as a set of actions aimed at protecting the patient and preventing adverse events (AE), described as incidents that result in unnecessary damage during care provided in health services.¹

Organizations and health professionals have been discussing AE from the 'To Err is Human' Report, whose information sparked a worldwide movement in search of patient safety.² In 2004, the World Health Organization (WHO) launched the World Alliance for Patient Safety with the objective of providing guidelines for the systematization of safe care for the population.³

In Brazil, in 2013, the Ministry of Health instituted the National Patient Safety Program (*PNSP*) with the aim of contributing to the qualification of healthcare and encouraging the consolidation of a safety culture involving health professionals, managers, patients and their caregivers in actions and strategies aimed at patient safety.⁴ The inclusion and participation of the family and the patient in actions to promote patient safety together with the health team is an important aspect in the care qualification process provided.^{5,6}

The term 'patient participation' can be defined as patient involvement in the decision-making process in relation to health issues.⁷ Based on this principle, the aim is to enable patients to have knowledge about their health status, to be encouraged to interact with professionals and participate in the decisions of their care plan.^{8,9} From this perspective, the WHO created the 'Patients for Patient Safety' campaign, with the objective of including patients and caregivers in the promotion of safe care and ensuring that their needs are respected during health care.¹⁰

A study carried out by the University of Washington with 2,078 patients showed that, during hospitalization, 98% of patients and caregivers are able to act to reduce the risk of AE.¹¹ However, it is highlighted that some barriers compromise the efficiency of involvement in safety actions, such as the lack of information on how to interact with the team and how to act in care, in addition to the perception of subordination to professionals.^{12,13}

In light of the above, it is evident that the involvement of the patient and caregiver, despite being recommended for the promotion of patient safety, is permeated by challenges in the practical context,

requiring that patient and family inclusion strategies be discussed with this purpose.¹²

Therefore, the guiding question arises: 'What evidence are available in the literature about the strategies for involving patients and caregivers in patient safety actions in hospital units?'

It is believed that this study can provide support for health professionals and managers to rethink more effective ways to develop and implement strategies to promote more involvement of the patient and caregiver in patient safety and prevention of adverse events. In addition, managers will be able to implement training strategies so that professionals feel more prepared to guide and deal with the family and patient who will be co-participants in safe care. In this sense, this study aimed to describe the evidence available in the literature on the strategies for involving patients and caregivers in actions to promote patient safety in hospital units.

METHODOLOGY

It is an integrative review (IR) that constitutes one of the methods used in evidence-based practice with the objective of gathering, synthesizing, and evaluating the results of studies on a given theme or issue, in a systematic and orderly manner, contributing to the exploration of the investigated topic, in addition to presenting knowledge gaps that need to be unveiled with new studies.¹⁴

For the elaboration of the IR, six distinct stages were developed, namely: a) formulation of a research question with relevance to health and Nursing; b) search in the databases to select the studies that were included in the review and establish criteria for inclusion and exclusion of studies; c) definition of the information to be extracted from the selected studies; d) evaluation of publications included in the IR; e) interpretation of results; f) presentation of the main findings evidenced by the analysis of the articles included.¹⁴

The construction of the guiding question was inspired by the PICO strategy, which is an acronym, where P stands for 'population' (patients and caregivers of hospitalized patients); I of 'intervention' (strategies for the inclusion of patients and caregivers in patient safety); C for 'comparison' (not applicable, as this is not a comparative study) and O for 'outcome' (involvement of the patient or caregiver in patient safety actions).¹⁵

The databases searched were: Latin American and Caribbean Literature on Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Scopus, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Cochrane Library. To select the search terms, the Health Sciences descriptors (DeCS) from the LILACS databases were used; the Medical Subject Headings (MeSH), owned by the PubMed portal; the Scopus, Web of Science, and Cochrane databases; and in the CINAHL titles, owned by the CINAHL database. Thus, the following descriptors were defined: 'Patient involvement', 'Patient involvement', 'Patient engagement', 'Patient Engagement', 'Family participation', 'Family participation', 'Family involvement', 'Family involvement', 'Family engagement', 'Family engagement', 'Involvement, Involvement', 'Engagement', 'Engagement', 'Patient safety', 'Patient safety'. The search strategies used were aided by the Boolean logical operators AND and OR.

The inclusion criteria were original articles, with full text, published in Portuguese, English or Spanish, between 2005 and 2020, relevant to the guiding question of the study. The time frame is justified by the increase in initiatives around the theme from 2004 onwards. Duplicate articles or articles that did not meet the objective of this review were excluded.

Initially, the articles were pre-selected through a meticulous reading of titles and abstracts, with the intention of verifying whether they were consistent

with the objective of the research. Then, the articles were read in full to select those that had evidence related to the study. For data collection and analysis, an instrument was used, including a list of questions that assessed the level of relevance and critical analysis of the results in order to safeguard methodological rigor.¹⁶ This phase was carried out by two independent researchers. When consensus was not possible, a third researcher was consulted.

For the categorization of the level of evidence, the proposed by Melnyk and Fineout-Overholt¹⁷ was adopted, in which the quality of evidence is classified into seven levels, namely: level I - evidence from systematic review or meta-analysis of relevant randomized controlled clinical trials or originated from clinical guidelines based on systematic reviews of randomized controlled clinical trials; level II - evidence obtained from at least one well-designed randomized controlled clinical trial; level III - evidence obtained from well-designed clinical trials without randomization; level IV - evidence from well-designed cohort and case-control studies; level V - evidence originating from a systematic review of descriptive and qualitative studies; level VI - evidence from a single descriptive or qualitative study; level VII - evidence from the opinion of authorities and/or report from expert committees. According to the classification, levels 1 and 2 are considered strong evidence, 3 and 4 moderate and 5 to 7 weak.

Figure 1 illustrates the selection flow of the articles included in this study.

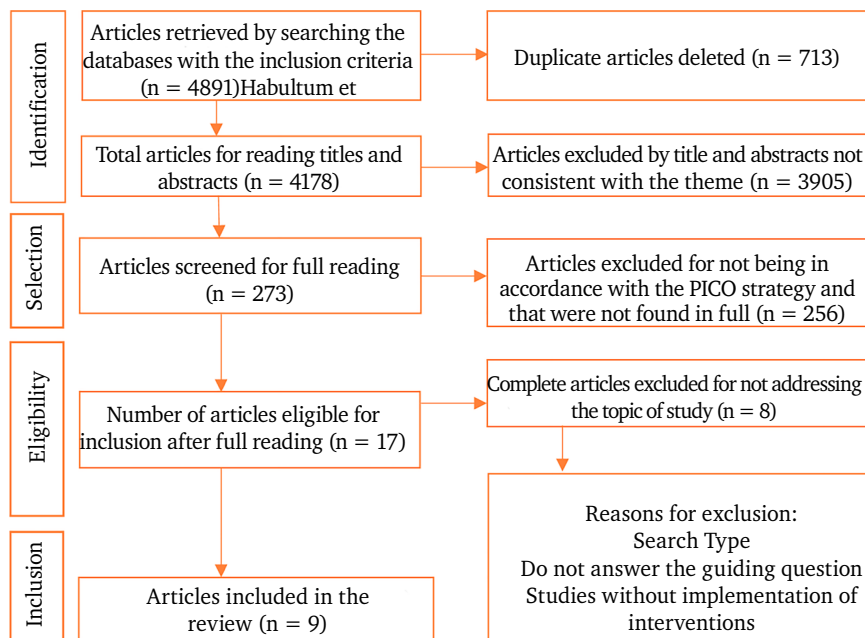


Figure 1 - Flowchart of identification, selection, inclusion, and exclusion of integrative review studies - Belo Horizonte, MG, Brazil, 2020

RESULTS

Table 1 presents the description of the studies according to author, year, objective, strategies used, methodological design, main findings, and level of evidence.

Table 2 presents a summary of the selected studies in relation to the potential and limitations of the strategies for involving patients and caregivers in patient safety actions.

Table 1 - Characteristics of the studies included in the integrative review. *Belo Horizonte, Minas Gerais, Brazil, 2020*

Author and Title	Year and Country	Objective	Strategies for involving patients and caregivers in patient safety actions	Methodological Design	Results and Strategies	Evidence Level
Betsie GI van Gaal <i>et al</i> <i>A1¹⁸ 'Fewer adverse events as a result of the SAFE or SORRY? programme in hospitals and Nursing homes. Part I: primary outcome of a cluster randomised trial'</i>	2011 Netherlands	Test the effect of the SAFE or SORRY method? in the incidence of adverse events in patients	Multi-faceted strategy including health education, patient engagement experience and feedback through a computerized recording program and an implementation plan	Type of Study: Randomized trial. Setting: General wards and elderly clinic. Participants: 2,201 patients from general wards and 392 patients at an elderly clinic	The results showed 43% less AE in the hospital environment and 33% in the out-of-hospital setting after the intervention, compared to the usual care groups	Level II (strong)
Davis RE, Pinto A, Sevdalis N, Vincent C, Massey R, Darzi A <i>A2¹⁹ 'Patients' and health care professionals' attitudes towards the PINK patient safety video'</i>	2012 United Kingdom	Examine the attitudes of patients and healthcare professionals towards a video that aims to promote patient involvement in patient safety	Animated video was produced with the aim of helping patients to prevent errors. After the video, a questionnaire was applied to assess attitudes towards patient safety	Type of Study: Exploratory study. Setting: Clinical and surgical ward. Participants: 201 patients and 95 health professionals	The patients showed more positive attitudes towards the professionals' questions regarding hand hygiene. In the professionals' perception, the video had more impact in relation to the questioning about hand hygiene, in addition to the perception that patients were more involved in patient safety	Level VI (weak)
Schwappach DLB, Frank O, Buschmann U, Babst R <i>A3²⁰ 'Effects of an educational patient safety campaign on patients' safety behaviours and adverse events'</i>	2012 Switzerland	Investigate the effects of a patient safety warning on patients' perceptions of risk, perceived behavioral control, performance of safety behaviors, and adverse incident experience	Disclosure of information in the initial care through warnings about patient safety, especially in relation to the perception of risk	Type of Study: Quasi-experimental study Setting: Surgical department. Participants: 218 patients in the control group and 202 in the intervention group	Patients in the intervention group were less likely to feel poorly informed about AE (p=0.043) and to experience any safety-related incident (p=0.009). Perceived behavioral control was lower in the control group (p=0.010)	Level IV (moderate)

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Table 1 - Characteristics of the studies included in the integrative review. *Belo Horizonte, Minas Gerais, Brazil, 2020*

Author and Title	Year and Country	Objective	Strategies for involving patients and caregivers in patient safety actions	Methodological Design	Results and Strategies	Evidence Level
Hrisos S, Thomson R. A4²¹ <i>'Seeing It From Both Sides: Do Approaches to Involving Patients in Improving Their Safety Risk Damaging the Trust Between Patients and Healthcare Professionals? An Interview Study'</i>	2013 United Kingdom	Explore, from the perspective of patients and the healthcare team, the possible consequences of patient-mediated intervention as a way to promote patient involvement in patient safety	Use of a themed guide on how patients can get involved in their own care, plus international campaign materials	Type of Study: Qualitative study. Setting: General and surgical ward. Participants: 16 patients, 4 family members and 39 health professionals	The participants of the study independently of the group, they showed if interested in participate in the actions of patient safety, in addition to recognizing benefits such as improved treatment adherence and more satisfaction with the service	Level VI (weak)
Davis RE, Sevdalis N, Pinto A, Darzi A, Vincent CA A5²² <i>'Patients attitudes towards patient involvement in safety interventions: results of two exploratory studies'</i>	2013 United Kingdom	Assess attitudes of the patients in regarding a video and leaflet with the purpose of encourage the involvement of patient in patient safety	The patients of the group 1 watched the video PINK with the aim to encourage them to involve in security of the patient and the group 2 patients read the leaflet who sought to instruct them about their treatment	Type of Study: Exploratory study. Setting: General and surgical ward. Participants: 106 patients in the study 1 and 95 patients in study 2	Both features increased to disposition of patients in themselves involve in patient safety	Level 6 (weak)
Dykes PC, Rozenblum R, Dalal A, Massaro A, Chang F, Clements M, <i>et al</i> A6²³ <i>'Prospective Evaluation of a Multifaceted Intervention to Improve Outcomes in Intensive Care: The Promoting Respect and Ongoing Safety Through Patient Engagement Communication and Technology Study'</i>	2017 United States	Examine the effectiveness of a patient-centered and patient-safe care and involvement program	Training was carried out on patient safety items, and on patient care planning tools, in addition to the development of a messaging platform for communication between the health team and patients	Type of Study: Prospective intervention study Setting: Intensive care unit Participants: 2,105 patients	The rate of adverse events was reduced from 59.0 per 1,000 patient-days to 41.9. Patient satisfaction improved from 71.8 to 93.3	Level 6 (weak)
Walters CB, Duthie E A7²⁴ <i>'Patient Engagement as a Patient Safety Strategy: Patients' Perspectives'</i>	2018 United States	Describe patient involvement as a patient safety strategy from the perspective of hospitalized surgical cancer patients	Standardization of direct messages was used, such as 'your safety' and not 'patient safety'; clear and objective instructions, in addition to teaching patients about specific actions on the subject of patient safety	Type of Study: Descriptive qualitative study Setting: In-patient unit. Participants: 13 patients	As patients accept to follow the instructions provided by professionals with regard to patient safety, nurses have improved communication with the patient	Level 6 (weak)

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Table 1 - Characteristics of the studies included in the integrative review. *Belo Horizonte, Minas Gerais, Brazil, 2020*

Author and Title	Year and Country	Objective	Strategies for involving patients and caregivers in patient safety actions	Methodological Design	Results and Strategies	Evidence Level
Khan A, Spector ND, Baird JD, Ashland M, Starmer AJ, Rosenbluth G, <i>et al</i> A8 ²⁵ 'Patient safety after implementation of a coproduced family centered communication programme: multicenter before and after intervention study'	2018 United States	Determine whether adverse events, family experience, and communication processes improved after implementing the intervention	The intervention was based on standardizing the dialogue between the health team and the family. Communication was based on the I-PASS mnemonic (severity of the disease, patient summary, list of actions, situation awareness and contingency planning and synthesis by recipient), in addition to daily reports of the rounds performed	Type of Study: Clinical study without randomization. Setting: Pediatric units. Participants: 2,148 parents or caregivers, 435 nurses, 203 medical students and 586 residents	Preventable and non-preventable adverse events had a statistically significant reduction (p=0.01 and p=0.003 respectively, post-intervention. Family involvement in care increased, as well as communication processes and patient experience improved after implementation	Level 4 (moderate)
Gonçalves KMM, Costa MTTCA, Silva DCB, Baggio ME, Corrêa AR, Manzo BF A9 ²⁶ 'Playful strategy to promote the engagement of parents and caregivers in pediatric patient safety'	2020 Brazil	Evaluate a playful strategy to promote the engagement of parents and caregivers in child safety	Execution of a game aimed at the patient safety area, held with parents and caregivers	Type of Study: Descriptive qualitative study/ action research. Setting: Pediatric units. Participants: 17 caregivers of hospitalized children	The game was an important knowledge transfer tool on the caregiver's involvement in patient safety. Participants stated that after the game they felt more confident and motivated to get involved in patient safety actions	Level 5 (weak)

Table 2 - Potential and limitations of patient and caregiver involvement strategies in patient safety actions. *Belo Horizonte, Minas Gerais, Brazil, 2020*

Type of Strategies	Potentials	Limitations
Strategies with different teaching resources (A1) ¹⁸	Possibility of addressing various topics and using various educational technologies for the same purpose, increasing the effectiveness of the strategy (A1) ¹⁸	Implementation complexity (A1) ¹⁸ Need for more time to implement the strategy (A1) ¹⁸
Multimedia resources (A2) ¹⁹ and (A5) ²²	Easy to understand for patients who have a low level of education due to the visual approach (A2) ¹⁹ and (A5) ²²	Need for careful evaluation of video scenes to meet all audiences (A5) ²²
Booklet with information (A4) ²¹ and (A5) ²²	Can be useful in sharing campaigns and knowledge dissemination (A4) ^{21,22} Easy to understand (A4) ²¹	Need to evaluate the layout to prevent misinterpretation (A5) ²²
Technological resources (A6) ²³	Several possibilities for the patient to get involved and get to know their care in a creative way (A6) ²³	High cost in the investment of necessary materials (tablets and computers) (A6) ²³
Questionnaires to find out about patients' questions (A3) ²⁰	Easy to implement and doesn't require a lot of investments (A3) ²⁰	Requires minimal patient literacy (A3) ²⁰ Risk of unreliable answers (A3) ²⁰
Dialogued interviews (A4) ²¹ and (A7) ²⁴	Possibilities of interviewee insights (A7). ²⁴ Closer to the patient (A4) ²¹ and (A7) ²⁴	Possibility of dispersing from the main theme (A7) ²⁴
Round tables (A8) ²⁵	Multidisciplinary insertion (A8). ²⁵ Interaction with the patient and caregiver (A8) ²⁵	Pay attention to the duration of the round tables and criteria for choosing the location to avoid dispersion (A8) ²⁵
Playful strategy (A9) ²⁶	Interaction with caregivers and parents in a playful and relaxed way (A9) ²⁶	Need to assess appropriate location (A9) ²⁶

DISCUSSION

This review made it possible to describe different strategies that were developed in health settings in order to involve the patient and caregiver in patient safety.

Study A2¹⁹ used a video on patient involvement, which showed promising results related to a more questioning posture on the part of patients. Study A5²² added a booklet to the video with informative and complementary content, in order to enhance the impact on the change in behavior, attitude and knowledge of patients. In this sense, the authors emphasize that the use of quality videos can favor the empowerment of users to be involved in their own safety, in addition to helping to promote educational campaigns in favor of patient safety.^{22,27} Although the video strategy contributes to strengthening shared decisions, consolidating knowledge and educating patients about issues related to their health, there are precautions to be considered in relation to the images chosen and the language used.^{27,28} Study A5²² warns of possible negative consequences of using video, since in some patients it can trigger anxiety resulting from the risks to which they are exposed.²⁹

The educational video consists of a technical pedagogical device, composed of verbal, visual and sound language. In addition, it encourages the viewer to form an analytical sense and active role performance in their health issues.³⁰

However, research warns that videos have limitations related to interference in the process of transmission and reception of information. Therefore, the association of audiovisual resources with verbal guidance can resolve the demands related to the patients' individualities, so that the proposal is effective.³¹

Another educational strategy presented was the use of booklets and leaflets considered to be more financially viable and effective in transmitting knowledge.³⁰ Two studies used these resources to present participants with a series of materials from international and local campaigns on topics related to patient safety and encourage patients to participate in their own care.^{21,22} A weak point presented by the participants of study A5²² was the unavailability of the booklet after the intervention.

The playful strategy was presented in article A9²⁶, with the participation of parents and pediatric caregivers.

The results observed in the study showed that the participants considered the teaching strategy, creative, informative, in addition to reporting that after the game they felt more confident in participating in the care of their children and encouraged to question professionals regarding their doubts and procedures.²⁶ Playful strategies are methods that have been used in order to produce information and encourage the participation of patients and caregivers in care, but initiatives are still incipient in the area of patient safety.^{26,32-34}

The studies exposed data on patients' fear of displeasing professionals when they participate in actions to promote their safety, as they start to question more, in addition to remaining more attentive to the care provided.^{21,22,24} Articles A7²⁴ and A8²⁵ showed evidence similar results and highlighted the importance of optimizing the bidirectional communication process (professional/patient) to avoid embarrassment.

After the standardization of communication during the round tables, the understanding of the caregiver and the patient about the health status, procedures and care became better and the participants expressed more satisfaction and ability to apply the recommendations.²⁵ In study A9²⁶, in which a playful intervention was applied, the caregivers felt empowered and encouraged to participate in childcare and patient safety.

The level of education and literacy of patients is an aspect that must be considered for the effectiveness of any approach to health. In this review, study A3²⁰, which uses a questionnaire as an intervention, addresses whether the level of education can be a limitation, especially with regard to strategies that require reading or understanding complex terms. From this perspective, health literacy is necessary, which is described as obtaining a level of knowledge and personal skills, through the understanding, evaluation and practical implication of health information and guidelines.³⁵

The synthesis of the studies reveals important contributions with the implementation of strategies for the involvement of the caregiver and the patient in patient safety, but investment in the training process of professionals is necessary to deal with the family and patient. Training in quality and patient safety through the development of innovative programs that contribute to aligning the education of the multidisciplinary team, in addition to preparing them to work in an integrated manner with the family, is extremely important to achieve safe care.³⁶

Thus, it is essential to reflect on the role of professional training centers on the subject of patient safety, given the existence of gaps in the curriculum. In 2011, the WHO launched a guide to help educate healthcare professionals in training on patient safety, entitled 'Patient Safety Curriculum Guide: Multi-professional Edition', which aims to instrument the improvement process.^{37,38}

From this perspective, it is important to rethink teacher preparation to incorporate the subject of patient safety in the teaching-learning process of students still in training and, thus, positively influence both the formation of the professional identity of students and the improvement of health care.³⁹

As a limitation, there is the scarcity of productions with a high level of evidence and the emphasis on qualitative studies that portray the perception of professionals, patients and families regarding the patient and caregiver's involvement strategies in patient safety. It is suggested the need to develop quantitative studies that can assess the different strategies for inclusion of the family and patient in patient safety regarding impacts, costs of actions and analysis of indicators of adverse events.

CONCLUSIONS

It was possible to observe different strategies, such as the use of videos, booklets, dialogued interviews, technological tools, or multifaceted health education, which enable more participation of patients and caregivers in patient safety. It is suggested that educational technologies be developed and articulated with each other or implemented in isolation, according to the reality and specificity of each service, in addition to evaluating the profile of the participants. Furthermore, it is recommended to increase the discussion and training on patient safety among professors, students, and health professionals, seeking the inclusion of the family and the patient in safe care.

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