Patient safety in hospital care: a review of the patient’s perspective

Segurança do paciente no cuidado hospitalar: uma revisão sobre a perspectiva do paciente

Seguridad del paciente en el cuidado hospitalario: una revisión sobre la perspectiva del paciente

Abstract

The goal was to review the literature on incidents and adverse events and their contributing factors in hospital care, described according to the patient’s perspective. A review was carried out of articles published in the MEDLINE, Scopus and LILACS databases between 2008 and 2019. From the 2,686 studies initially found, 167 were pre-selected for reading and then 24 were selected and classified based on a thematic analysis of their content. Four categories resulted from the information extracted from the 24 articles: terminology used to define incidents and adverse events, especially different terms such as error and medical error; incidents and adverse events identified by patients, family members and caregivers related to medication, surgery, health care-related infections, falls and pressure injuries; patients’ perception of factors that contribute to unsafe care, especially problems related to communication, hand washing and patient identification; suggestions from patients to prevent the occurrence of incidents and adverse events, including training staff, drawing up checklists, listening to patients and adapting the environment. Patients were able to identify incidents, adverse events and contributing factors in health care. Alongside information from staff, their reports can potentially contribute to the provision of safer health care.

Patient Safety; Patient-centered Care; Patient Preference; Patient Participation

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Introduction

Patient safety became a worldwide concern in the early 2000s following the release of the report *To Err Is Human: Building a Safety Health System* by the U.S. Institute of Medicine (IoM) 1. Despite the advances, new challenges and priorities have emerged in the two decades since its publication, such as diagnosis errors and outpatient safety 2. During this period, efforts have been made to listen to and learn from reports of adverse events provided by patients 2,3.

In this sense, since 2013 the Patients for Patient Safety program of the World Health Organization (WHO) has encouraged the incorporation of patient, family and community experience at all levels of health care, aiming at their involvement and empowerment. The ultimate goals of this program are to defend and support patients so they may take ownership of their own care; to give a voice to patients and people in charge of health care; and to promote partnerships among patients, family members, community, health care staff, policy makers and academia 4.

In line with international initiatives in the area of patient safety, Brazilian National Program for Patient Safety (PNSP, in Portuguese) advocated patient participation in one of the four core areas, emphasizing the importance of humanization, effective communication and viewing patients as a relevant factor in preventing the occurrence of incidents and adverse events 5. The literature on patient safety describes incidents as events or circumstances that might have resulted, or resulted, in unnecessary harm to the patient. In turn, adverse events are incidents that resulted in harm to the patient, extending hospital stay or disability 5. In short, they are undesirable results during health care provision deriving from a range of contributing factors, defined as circumstances, actions or omissions, which play a key role in the origin, development or increased risk of an incident 5,6.

Considering that patients and family members identify incidents and adverse events that go undetected by staff, the incidents reported by staff are those with the most immediate and visible clinical impact. As the health care experiences perceived by patients happen in different clinical situations over the years, they may often be invisible to most staff, not only because the latter are reluctant to recognize them, but also due to lack of available information 7.

Patients are able and willing to report incidents and contributing factors without embarrassment or harm, providing new and valuable information about the type and frequency of these occurrences, which do not necessarily appear in health care staff records and notification systems 6. Even when patients’ reports on care safety problems overlap with those of staff, they can provide additional information, helping to better understand the scope of such problems and the factors that contribute to their occurrence 8. Thus, patients’ reports offer a different perspective on hospital care safety, and their experience, which usually goes undetected in information systems, can contribute to improve the quality of health care and shared decision-making.

The issues related to health care safety identified by patients cover a wide spectrum of problems, such as medication errors, care communication and coordination, infections, delayed diagnosis and treatment, failures in blood collection, procedures in the wrong patient or wrong part of the body and faulty equipment 9,10. Therefore, the analysis of incidents identified by patients, besides those reported by staff, can contribute to a more complete overview of safety issues 7. In this sense, knowing the views of patients and relatives has become a priority, helping to build patient-centered care processes and to improve the performance of clinical teams and organizations 11.

The concepts of patient empowerment, engagement, experience and participation have been used to support strategies and initiatives aimed at organizational learning and improved quality of health care services, especially patient safety 12. Intensely debated in several countries 10,11,13, this issue is still poorly addressed in developing countries like Brazil.

Given the importance of the view of patients and relatives to patient safety and the lack of studies on this subject in Brazil, the goal of this study is to review the literature on incidents and adverse events and their contributing factors in hospital care, described according to the patient’s perspective.
Method

Type of study

This is a literature review with a systematic search. The guiding question of the study was: “What are the incidents and adverse events and their contributing factors identified by patients, their families and caregivers in hospital care?”.

Search and selection

The following information sources were chosen for the article search: MEDLINE via PubMed, Scopus via Portal de Periódicos from Brazilian Graduate Studies Coordinating Board (CAPES) and LILACS via Virtual Library of Health (VHL). These databases were chosen for containing a wide range of national and international studies on health care with public access or available through a library.

The search terms were selected after an exploratory reading of the subject. The Medical Subject Headings Terms (MeSH) of the U.S. National Library of Medicine (NLM) provided the following terms: patient safety; patient-centered care; patient participation; risk management and consumer participation. In turn, the following terms were found as health science descriptors in Latin American and Caribbean Center on Health Sciences Information – Bireme (DeCS): segurança do paciente (patient safety); perspectiva do paciente (patient preference); cuidado centrado no paciente (patient-centered care); and participação do paciente (patient participation). After testing the bibliographic databases, the following terms were used: segurança do paciente (patient safety); notificações de pacientes (patient reports); perspectiva do paciente (patient perspective); cuidado centrado no paciente (patient-centered care); engajamento do paciente (patient engagement); participação do paciente (patient participation); experiência do paciente (patient experience); notificações da experiência do paciente (patient reporting experience); and notificações de incidentes (reporting incidents). The combination of these terms comprised the search strategies described in Table 1. The data were collected in June-August 2019 and updated in March 2020. Zotero Standards One software (https://www.zotero.org/) was used to manage references, eliminate duplicates and organize the articles.

Eligibility criteria

The inclusion criteria for the articles were: focus on patient safety from the patient’s perspective; occurrence of incidents and/or adverse events and contributing factors from the patient’s perspective; empirical quantitative or qualitative study based on hospital care, during hospitalization or after hospital discharge, of adult patients (over 18 years old); information from actual patients or their relatives and caregivers.

The exclusion criteria for the studies were: perspective of staff and students; patient safety specifically related to medication use; patient safety in the treatment of specific diseases such as cancer, diabetes, lung and orthopedic diseases, circulatory, digestive and renal system diseases, among others; in obstetric or maternity care; in primary health care; in pediatrics and neonatology care; in mental health; in diagnostic and therapeutic use of radiation-generating devices; in laboratories; in dentistry; in home care; and studies specifically addressing patient satisfaction. Other studies not included in the above categories but which were unrelated to the research subject, such as those addressing violence, environmental health and health surveillance, were also excluded. Also excluded were reviews, opinion articles, editorials, letters, interviews, books and book chapters, theses, monographs, dissertations and term papers, plus gray literature. Therefore, the focus was on articles resulting from empirical studies with different methodological approaches, published in scientific journals and submitted to peer review. This stage also included the reading of titles and abstracts of all studies cited in the bibliographic references of the 24 selected works. In this stage, 16 articles were selected for complete reading, and five articles were included after the exclusion criteria had been applied.
Table 1

Search strategies used in the bibliographic databases, 2020.

| Databases                          | Terms used                                                                                                                                                                                                 | Publications (n) |
|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| LILACS via VHL                     | tw:(tw:("patient safety" OR "segurança do paciente") AND (tw:"risk management" OR "Consumer participation" OR "patient participation" OR "segurança do paciente" OR "reporting incidents" OR "Patient reports" OR "patient perspective" OR "patient-centered care" OR "patient engagement" OR "patient participation" OR "patient experience" OR "patient reporting experience")) AND (fulltext:"1") AND db:"LILACS") AND limit:"humans" OR "female" OR "male" OR "adult" OR "aged") AND la:"pt" OR "en" OR "es") AND year_cluster: ("2016" OR "2015" OR "2018" OR "2017" OR "2014" OR "2019" OR "2013" OR "2012" OR "2010" OR "2011" OR "2009" OR "2008") | 739              |
| MEDLINE via PubMed ("patient safety"[Title/Abstract] OR "patient safety"[MeSH Terms]) AND ("risk management"[MeSH Terms] OR "consumer participation"[Title/Abstract] OR "patient participation"[MeSH Terms]) OR "patient participation"[Title/Abstract] OR "reporting incidents"[Title/Abstract]) OR ((("patient reports"[Title/Abstract] OR "patient centered care"[Title/Abstract]) OR "patient perspective"[Title/Abstract]) OR "patient participation"[MeSH Terms]) OR "patient experience"[Title/Abstract]) OR "patient reporting improvement"[Title/Abstract] OR "safety management"[Title/Abstract]) AND ("loattrfree full text"[sb] AND "loattrfull text"[sb]) AND ("2008/01/01"[PDAT]: "2019/12/31"[PDAT]) AND "humans"[MeSH Terms]) | 1,554            |
| Scopus ("patient safety" AND TITLE-ABS-KEY ("risk management" OR "Consumer participation" OR "patient participation" OR "reporting incidents" OR "Patient reports" OR "patient perspective" OR "patient-centered care" OR "patient engagement" OR "patient participation")) OR TITLE-ABS-KEY ("patient experience" OR "patient reporting experience") AND (LIMIT-TO (DOCTYPE, "ar") OR LIMIT-TO (DOCTYPE, "ch") OR LIMIT-TO (DOCTYPE, "sh") OR LIMIT-TO (DOCTYPE, "bk") AND (LIMIT-TO (PUBYEAR, 2019) OR LIMIT-TO (PUBYEAR, 2018) OR LIMIT-TO (PUBYEAR, 2017) OR LIMIT-TO (PUBYEAR, 2016) OR LIMIT-TO (PUBYEAR, 2015) OR LIMIT-TO (PUBYEAR, 2014) OR LIMIT-TO (PUBYEAR, 2013) OR LIMIT-TO (PUBYEAR, 2012) OR LIMIT-TO (PUBYEAR, 2011) OR LIMIT-TO (PUBYEAR, 2010) OR LIMIT-TO (PUBYEAR, 2009) OR LIMIT-TO (PUBYEAR, 2008) AND (LIMIT-TO (LANGUAGE, "English") OR LIMIT-TO (LANGUAGE, "Spanish") OR LIMIT-TO (LANGUAGE, "Portuguese")) | 512              |

Source: prepared by the authors.

Identification of studies, selection and data extraction

The studies selected for the review were complete, available and accessed through a library, written in English, Spanish and Portuguese, regardless of the methodological approach (quantitative or qualitative) and study design (including experimental, observational, semi-experimental and correlational, among others), and published between January 2008 and December 2019. The time frame was chosen due to the importance of the Patients for Patient Safety program 4 created by WHO in 2013 to expand the global discussion on the subject; therefore, the period spanning from 2008 to 2019 was selected for this review, that is, 5 years before and 5 years after the aforementioned program was instituted, in order to identify both publications that provide input for the program and those that report on its results or developments.

The selected articles were organized in a synoptic table featuring the following variables: authors; year of publication; study location/country; study design; goals; main results. The terminology used to define incidents and adverse events was also considered.

A narrative synthesis of the information collected from each article was carried out, grouped into categories according to the content analysis, namely: (i) terminology used to define incidents and adverse events; (ii) incidents and adverse events identified by patients, relatives and caregivers; (iii) patients’ perception of factors contributing to unsafe care; and (iv) patients’ suggestions to prevent the occurrence of incidents and adverse events. The first category was based on the International Classification for Patient Safety – ICPS) 6, whose key concepts are: notifiable circumstance, near miss, incidents and adverse events. The second and third categories considered the six WHO international
patient safety goals, adopted in Brazil: (1) identify patients correctly; (2) improve effective communication; (3) improve the safety of highly-alert medications; (4) ensure safe surgery; (5) reduce the risk of health care-associated infections; (6) reduce the risk of patient harm from falls. The fourth category resulted from the need for organizational learning derived from the perspective of patients and relatives on safer care.

The selected articles were read in full and their content related to the above categories. The methods and results were described, with the latter highlighted, analyzed and interpreted in light of the theoretical and conceptual literature on health care quality and patient safety. The relevance of the previously defined categories was confirmed, and therefore they were reinforced in the reading and maintained. Some studies covered more than one category.

Results

Following the removal of duplicates from the initial 2,805 articles identified, 2,686 articles remained. After the reading of titles, abstracts and keywords, 2,519 studies were excluded; 42.8% were excluded for addressing patient safety from the perspective of staff, 18.5% were not related to the subject and 7.7% addressed patient safety in using medication (Table 2).

After this stage, application of the inclusion and exclusion criteria resulted in the selection of 172 articles. At the end of this process, 29 articles were selected considering the guiding question (Figure 1).

Of the 29 selected publications, 17.2% were published in 2018 and 2016, 13.7% in 2015 and 2008, 10.3% in 2013 and 6.8% in 2017 and 2012. Only one publication was identified in the other years and none in 2010. Canada was the country with the largest number of papers (20.6%), followed by England (17.2%) and the United States (13.7%). Most of the articles were published in English, totaling 79.3% of the studies (Box 1).

As for study design, it was observed that most of the articles (37.9%) used mixed methods and the same proportion (31%) adopted qualitative approaches. There was variation in sample size and type according to quantitative and/or qualitative design. One quantitative study included 25,098 participants, while a qualitative study was carried out with 11 patients.

Most studies were performed with patients after and during hospitalization. Three studies used notification systems of incidents and adverse events for patients. In two studies the time of data collection was not informed.

The study that identified the highest proportion of patients that were concerned about or reported incidents and adverse events in health care was conducted in the United States, with a 65% occurrence rate among sampled cases. The work with the lowest proportion was also carried out in that country and found 4.3% of reports of some type of incident.

Terminology used to define incidents and adverse events

Considering the ICPS, different terminologies and concepts were identified to address patient safety problems, such as: notifiable circumstances, near miss, incidents and adverse events (Box 2).

Other terminologies were identified in the selected studies, among them: error; medical error; diagnostic error; clinical error; error with harm and error with injury; and medication error. Two studies used the terms unsafe situation and safety concerns reported by patients. Also employed were the terms security concerns, catastrophic events, adverse outcomes and unsafe situations.

Incidents and adverse events identified by patients

Prominent among incidents and adverse events reported by patients were problems related to medication. Switched medication was the main concern mentioned in six studies, while allergic reactions to drugs were addressed in another
Table 2

Reasons for excluding studies, 2020.

| Reasons                                               | n  |
|-------------------------------------------------------|----|
| Monograph                                             | 1  |
| Term paper                                            | 1  |
| Thesis                                                | 1  |
| Interview                                             | 3  |
| Patient satisfaction study                            | 5  |
| Unavailable for free or through a library              | 5  |
| Letter                                                | 6  |
| Dissertation                                          | 7  |
| Patient safety and homecare                           | 7  |
| Books                                                 | 8  |
| Patient safety in dentistry                           | 8  |
| Studies in other languages                            | 11 |
| Patient safety in students' perspective               | 11 |
| Patient safety in laboratories                        | 11 |
| Patient safety in use of medical equipment            | 12 |
| Opinion articles                                      | 15 |
| Patient safety instruction                            | 15 |
| Patient safety and mental health                       | 15 |
| Patient safety in maternity and obstetrics care       | 16 |
| Patient safety in the use of radiation-generating devices | 19 |
| Abstract not available                                 | 22 |
| Editorial                                              | 26 |
| Clinical trials                                       | 49 |
| Primary care studies                                  | 83 |
| Studies relates to pediatrics and neonatology          | 127|
| Reviews                                                | 147|
| Patient safety in treatment of specific pathologies (cancer, diabetes, orthopedics, circulatory system...) | 149|
| Patient safety in medication processes                 | 195|
| Unrelated to the subject                              | 467|
| Patient safety in staff perspective                    | 1,077|
| Total                                                 | 2,519|

Source: prepared by the authors.

five 18,19,28,36,37. Also reported were errors and incidents in administration; prescription and dispensation 35, such as prescribing a drug to which the patient was allergic and providing non-prescribed medication 23; wrong dosage and hemorrhage after administration of anticoagulant 18; wrong medication or patient unaware of which drug should have been administered and possible adverse effects 16,23,39,40,43; and patients’ knowledge about the medications being used 18,26.

In a study carried out in the United States, 56% of patients reported having suffered adverse events to medication 28. In Brazil, incidents related to drug administration were reported by 78.5% of the sampled patients, such as switched medication, wrong dose and allergic reaction 18. Concern about medication safety was also mentioned in the Chinese study, in which only 14% of patients considered themselves to be aware of the possible adverse effects of drugs used, while 48% said they had some knowledge and 38% reported not knowing anything 40.

Concerns about hospital-acquired infections appeared in 13 studies 16,17,19,21,23,27,28,36,37,38,39,40,43. In an Argentinian study, health care-associated infections (HAI) was the most frequent adverse
event, reported by 8.5% of patients. In turn, a study conducted in the United States reported that 184 patients experienced diagnostic errors, 85 (46.2%) of whom also reported HAI. Despite the concerns described in the study conducted in China, 28% of patients were not aware of the possibility of being infected in the hospital environment.
Box 1

Characteristics of selected studies, 2020.

| Study (year) | Country | Study design | Goals | Main results |
|--------------|---------|--------------|-------|--------------|
| Heavey et al. 26 (2019) | England | Qualitative; n = 28 narrative interviews with patients after discharge. | To explore the responsibility of patients for their own safety in clinical settings. | Personal experience and self-care were aspects of patient responsibility mentioned. Medication errors were mentioned in patients' reports. |
| Armitage et al. 27 (2018) | England | Qualitative; interviews with n = 329 hospitalized patients. | To compare the results of a new tool to identify incident reports with three other methods of detecting existing patient safety incidents and identify agreement between the studied methods. | 77 patients provided 155 patient safety concerns. Reported incidents were related to general care (40%); care provision (25%); communication (16%); medication (15%) and various issues (4%). |
| Giardina et al. 28 (2018) | United States | Qualitative; n = 465 records of patients and relatives. | To analyze the database where patients and relatives reported errors and explore factors that contribute to diagnostic errors. | 75.8% of the records indicated that the patient suffered at least one adverse event. The most frequent error reported by patients was diagnostic error (79.9%), followed by adverse events related to medication process (56%), surgery- or procedure-related error (54.3%) and hospital-acquired infection (46.2%). Patients could select more than one category. |
| Hagensen et al. 29 (2018) | Norway | Qualitative; n = 15 interviews with patients. | To present patients' perspectives on the occurrence, disclosure and response of health organizations to adverse events. | The analysis revealed three main topics regarding patients' experiences with adverse events: 1 – ignoring patient concerns or complication signs; 2 – lack of responsibility and error correction; and 3 – lack of support, loyalty and learning opportunities. |
| Jerng et al. 15 (2018) | Taiwan | Mixed methods; n = 343 complaints from patients admitted to intensive care units (ICU) and 686 complaints from general care wards. | To analyze and compare health complaints in the ICUs and general wards of a university teaching medical center to understand the types of complaints, and investigate the factors associated with the severity of the reported problems. | 1,259 complaints were identified, 441 in the ICUs and 818 in wards, classified as: respect and patients' rights (16% and 18.1%), respectively; communication (6.3% and 3.2%); listening (12.2% and 18.5%); institutional processes (4.1% and 11.4%); environment (40.8% and 33.3%); safety (4.3% and 2.7%); and quality (15.4% and 13%). |
| Sahlström et al. 35 (2018) | Finland | Quantitative; n = 656 electronic records. | To analyze safety incidents reported by patients and their use in Finnish health care organizations. | The identified incidents related to: information flow or management (32.6%); medication (18%); diagnosis (7.5%); operative procedure (6%); harm (5.5%); asepsis/hygiene (2.6%); invasive procedures (1.6%). |
| Walton et al. 16 (2017) | Australia | Mixed methods; n = 7,661 surveys with patients after hospital discharge and analysis of inpatients database. | To investigate the experience of patients who suffered adverse events in hospitals. | 474 (7%) respondents reported having suffered some type of adverse event. |

(continues)
| Study (year)          | Country     | Study design                                         | Goals                                                                 | Main results                                                                                                                                 |
|----------------------|-------------|------------------------------------------------------|----------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|
| Weingart et al. 17   | United States | Mixed methods; n = 37 reports by patients, family members and caregivers via telephone and Internet. | To develop and test a pilot prototype of a notification system for patient safety, the Health Care Safety Hotline. | Of the 37 reports, 20 were considered errors without harm and 15 errors with harm. Most of the problems reported were related to diagnosis or advice from health care staff. Also reported were delays in operations, superficial examination, inadequate staff and medication errors. Contributing factors reported include problems with communication, care coordination, access and staff response. |
| Bezerra et al. 18    | Brazil      | Mixed methods (descriptive cross-sectional study); n = 80 interviews with inpatients in pre- and post-operative care. | To identify the occurrence of incidents perceived by patients during hospitalization, analyze the opinion of users about the occurrence of incidents and classify the incidents perceived regarding type, causes and consequences. | 17 interviewees reported having noticed an incident, most of them related to medication process (78.5%). |
| Kemp et al. 19       | Canada      | Quantitative (phone survey); n = 25,098 patients.     | To analyze the association between patient safety indicators and patient experience scores to determine the risk adjusted with experiences reported by staff. | A total of 1,085 respondents (4.3%) reported having had at least one documented incident. The most frequent were hemorrhage (2%); events related to obstetrics (1.5%); surgery (1%); and infection (0.8%). |
| O’Hara et al. 20      | England     | Mixed methods [complex, multifaceted intervention (cluster randomized controlled trial)]; n = 379 inpatients. | To explore the feasibility of systematically collecting patient feedback on care safety; to explore the feasibility and acceptance of PRASE intervention by staff and to better understand how they use patient feedback to improve services. | Patients’ reports of safety concerns were about: dignity and respect; access to resources; communication and teamwork; delays; equipment; information flow; care organization and planning; staff roles and responsibilities; staff training; ward type and layout. |
| Okoniewska et al. 21 | Canada      | Mixed methods; n = 1,347 telephone interviews after hospital discharge and analysis of patients’ medical records. | To develop a conceptual model to assess the results of adverse outcomes reported by patients. | Of the 469 adverse outcomes reported by patients, 369 were reviewed and 7.9% classified as adverse events. |
| van Melle et al. 22   | Netherlands | Mixed methods; pilot study n = 13 patients interviewed and n = 12 records evaluated. | To investigate whether transient incidents can be identified based on hospital records to assess agreement between medical records and patient interviews. | 28 transient incidents were identified, of which 57% were classified as unsafe; 25% considered near miss; 25% errors that affected the patient without causing harm; and 18% adverse events. |
| Bishop & Cregan 30    | Canada      | Qualitative (videotaped interviews); n = 11 patients and family members. | To determine what patient and family narratives can say about a patient safety culture within health care organizations and how patients perceive a patient safety culture. | Three themes emerged: 1 – failure in care follow-up; 2 – no dialogue; 3 – the person behind the patient. |
### Box 1 (continued)

| Study (year) | Country       | Study design                        | Goals                                                                 | Main results                                                                                                                                 |
|--------------|---------------|-------------------------------------|------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|
| Gallardo et al. 36 (2015) | Argentina | Quantitative (cross-sectional descriptive); n = 37 inpatients. | To describe patients’ perception of safety regarding health care received during hospitalization. | The most common clinical error was infection (8.5%), followed by allergic reactions, diagnostic error (2.8%) and being mistaken for another patient (2.8%). |
| García-Diéguez 31 (2015) | Argentina | Qualitative; n = 28 inpatients divided into 4 focus groups. | To describe patients’ perception of their safety during hospitalization. | Dimensions and categories were defined based on the opinions provided by participants: staff/patient relationship; patient rights; quality of care process; perceived vulnerability; adverse events and error. |
| Meléndez Méndez et al. 37 (2015) | Mexico | Quantitative (descriptive and cross-sectional); n = 127 inpatients. | To determine patients’ perception of safety in relation to health care; to identify the number of patients who reported having suffered an error; and how the error was resolved during hospitalization in a hospital surgery service. | 29.9% of patients reported having suffered a clinical error during hospitalization. They reported having suffered an infection (7.1%), an allergic reaction (4.7%), undergone a second operation (10.2%), diagnostic error (3.2%), being mistaken for another patient (3.1%) and suffered an error in the administration of infections (1.6%). |
| Bishop et al. 38 (2014) | Canada | Quantitative; n = 217, survey with discharged patients. | To understand whether patient safety perceptions played a role in patient engagement in safety-related initiatives. | Overall, respondents were more likely to get involved in actual patient safety practices, such as sharing a list of used drugs with staff (88%) and always asking doctors about their health status (53.5%), than in challenging practices, such as asking staff whether they washed their hands (7.4%) or to confirm their identity before receiving medication or treatment (35%). |
| Davis et al. 23 (2013) | England | Mixed methods; n = 80 survey with patients after hospital discharge and analysis of medical records. | To investigate reports of unwanted events in health care of hospitalized patients. | 258 undesirable events were reported, including 136 (52.7%) interpersonal problems, 90 (34.8%) medical complications and 32 (12.4%) problems in the health care process. |
| Giles et al. 32 (2013) | England | Qualitative; n = 33 interviews with patients. | To explore to what extent patients are able to provide feedback on factors contributing to patient safety incidents. To develop indicators for each of the contributing factors in the form of a questionnaire, and test and validate this questionnaire with patients and professionals. | The following contributing factors were identified by patients: communication; individual patient-related factors; physical involvement; bed allocation and management; staff management; staff workload; dignity and respect; training and education; staff responsibility; equipment and supplies; supervision and leadership; factors related to team and support by superiors. |
| Howard et al. 33 (2013) | Australia | Qualitative; n = 16 interviews with patients and their representatives. | To explore the actions taken by patients who were admitted to acute care in a Queensland hospital and experienced dissatisfaction with the service provided. | The themes that emerged were: ineffective communication; disrespectful treatment; inconsistent care standards; perceptions of neglect; lack of information on how to file a complaint. |
| Study (year)      | Country       | Study design                                                                 | Goals                                                                                                                                                                                                 | Main results                                                                                                                                                      |
|------------------|---------------|------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Schwappach et al. 39 (2012) | Switzerland    | Quantitative (quasi-experimental intervention); n = 218 inpatients in the intervention group and 202 in the control group. | To investigate the effects of patient safety advice on risk perception, safety behaviors and patient incident experience.                                                                                   | Overall, patients reported infection (6%); medication error (5%); and believed that a medical error had happened in their care (5%).                              |
| Zhang et al. 40 (2012) | China          | Quantitative; n = 959 surgical patient questionnaires.                         | To investigate the initial status of patients' awareness, knowledge and attitudes towards their safety and determine the factors that influence patients' involvement in their own safety.           | One hundred and eighty-seven respondents (21%) have experienced a medical error; 18% have experienced nosocomial infections; and 14% of patients are aware of the side effects of medications being used. |
| Weingart et al. 24 (2011) | United States | Mixed methods; n = 2,025 telephone survey and review of medical records of patients, relatives and caregivers. | To understand to what extent inpatients took part in their care and how their participation related to care safety quality.                                                                             | 163 patients reported at least one adverse event during or as a result of hospitalization.                                                                       |
| Mira et al. 41 (2009) | Spain          | Quantitative; n = 384 survey with post-discharge patients.                    | To determine the perception of clinical safety among discharged patients.                                                                                                                                  | 31 patients reported a possible adverse event. 5.8% of cases were related to medication errors and 6.1% to surgery; in 2.3% both types occurred.                |
| Burns 34 (2008) | Canada         | Qualitative; n = 25 accounts by patients and family members.                  | To explore their stories as a learning tool and raise awareness about patient safety issues.                                                                                                               | Surgical complications or errors; errors in drug therapy; problems with procedures; birth complications; no diagnosis and misdiagnosis; neglect of patients; errors in emergency screening; and hospital-acquired infections. |
| Friedman et al. 25 (2008) | Canada        | Mixed methods; n = 201 interviews after hospital discharge and analysis of institutional database. | To determine whether patients and family members are able to identify adverse events in the emergency department, to characterize reports of errors identified by patients, and to compare patient reports with staff records. | 10 (5%) adverse events and 8 (4%) near misses were identified. Adverse events were mostly related to delays or inadequate analgesia.                        |
| Mira et al. 42 (2008) | Spain          | Quantitative; n = 336 surveys after hospital discharge.                       | To describe the frequency of clinical errors from the patients' point of view, their perception of safety and their relationship with the information received.                                              | 38 (13%) interviewees reported having suffered complications due to medication or surgical intervention. Of these, only 10.5% considered that the complications were serious. |
| Weissman et al. 43 (2008) | United States | Mixed methods; n = 998 surveys with patients after hospital discharge.        | To compare adverse events reported in post-discharge interviews with those detected in medical records.                                                                                                   | 23% of respondents reported having suffered at least 1 adverse event.                                                                                            |

Source: prepared by the authors.
Box 2

Terminology used in the selected studies to define incidents and adverse events.

| Terminology           | Study (year)                                                                 | Concept adopted                                                                 |
|-----------------------|------------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| Notifiable circumstance | Bezerra et al. 18 (2016)                                                      | A circumstance with significant potential to harm the patient.                    |
| Near miss             | Sahlström et al. 35 (2018); van Melle et al. 22 (2016); Burns 34 (2008)       | An incident that did not reach the patient.                                       |
| Incident              | Armitage et al. 27 (2018); Jerng et al. 15 (2018); Hagensen et al. 29 (2018); Sahlström et al. 35 (2018); Walton et al. 16 (2017); Bezerra et al. 18 (2016); Kemp et al. 19 (2016); van Melle et al. 22 (2016); Gallardo et al. 36 (2015); Meléndez Méndez et al. 37 (2015); Bishop et al. 38 (2014); Giles et al. 32 (2013); Schwappach et al. 39 (2012); Weissman et al. 43 (2008) | An incident that reached the patient but caused no harm.                           |
| Adverse event         | Hagensen et al. 29 (2018); Walton et al. 16 (2017); Bezerra et al. 18 (2016); Okoniewska, et al. 21 (2016); van Melle et al. 22 (2016); Bishop & Cregan 30 (2015); García-Diézquez 31 (2015); Davis et al. 23 (2013); Schwappach et al. 39 (2012); Zhang et al. 40 (2012); Weingart et al. 34 (2011); Mira et al. 41 (2009); Burns 34 (2008); Friedman et al. 25 (2008); Mira et al. 42 (2008); Weissman et al. 43 (2008) | An incident that harmed the patient.                                               |

Source: prepared by the authors.

Incidents related to surgery or procedures were a matter of concern in 11 studies 17,18,19,21,28,34,35,38,39,41,42. The following stand out among surgery-related problems reported by patients: presence of a foreign body, broken instrument in patient, intervention in wrong patient, incorrect surgical site 16,25,34,35, unexpected new surgery 23,37 and procedure-related harm 21, such as pain, tingling and numbness following venipuncture 18,23 and complications related to anesthesia and surgery 19,34,42.

Reports of falls appeared in seven studies 16,18,19,21,23,34,43. In one case the patient fell when trying to get up without the nurse’s help, as his request was not answered. Moreover, the accident was reported merely as a fall resulting in severe headache, with no professional assessment of the patient’s condition after the adverse event 18. The issue of pressure injury appeared in three studies with patients that had been discharged 19,23,43.

Other issues mentioned related to safe health care were diagnostic errors 15,16,17,21,22,23,25,28,29,34,35,36,37 and delayed diagnosis 15,28,29. Patients reported several types of diagnostic errors, such as: delayed diagnosis and treatment (76.1%); misdiagnosis of health problem in symptomatic patients (65.2%); failure to order necessary tests (48.4%); and lost, mislaid or disregarded test results (17.9%) 28. Also mentioned were failure to perform requested tests, unnecessary test repetition, cancelled tests and wrong test results 23.

Patient reports also mentioned more serious problems such as bleeding, bruising, pain and fractures, and central nervous system, obstetric, respiratory, cardiac, gastrointestinal and endocrine complications. Also reported were life-threatening events or risk to important organs, non-procedural harm, adverse events related to fluid control and venous thromboembolic events 17,19,23.

Patients’ perception of factors contributing to unsafe care

Patients’ perception of safety can influence the way they and their relatives engage in safe practices 38. Contributing factors related to communication, identification and hand washing were men-
tioned in patients’ reports, related to six safety goals. Other factors were also reported related to health care staff and team, and material and structural resources.

In the studies investigated, effective communication in exchanging and sharing information among staff, patients, groups, departments and services \(^{32}\) was identified as key factor and a potential trigger of problems in health care provision \(^{15,16,17,18,20,23,28,29,30,31,32,35,38,41}\). Issues related to communication were perceived by patients in different ways, such as problems related to respect and dignity \(^{20,23,31,32}\), listening to patients \(^{15,17}\), staff/patient relationship \(^{16,23,28,31}\), patient rights \(^{15,31}\) and information flow and management \(^{16,3,29,35}\).

Poor dialogue between staff and patients was emphasized. In a US study, patients most often complained of: not being heard, being ignored by the health team, reduced time of staff with patients and poor staff teamwork \(^{17}\). In some cases patients reported feeling they were just a number, with no proper care being given to the actual person behind the disease \(^{30}\).

Being treated with dignity and respect was another concern related to patient safety, as were staff training, care organization and planning, and roles and responsibility of the health care team \(^{20,23}\).

Four types of behavior problems were identified: staff ignoring patients’ knowledge; disrespect for patients by using pejorative language; failure to communicate information to patient and family; and staff manipulating information and using fear to influence the decisions of patients and relatives, or to misinform/withhold information from patients \(^{28}\).

Poor continuity and coordination in providing care were identified by patients as contributing factors to the occurrence of patient safety problems \(^{17,30}\). The presence of multiple staff often gave them a sense of fragmented care. According to patients, doctors were unable to provide a diagnosis based on the patient’s medical history, rather than only on manifest conditions and symptoms \(^{30}\). In this sense, communication is directly related to decision-making shared between staff and patients regarding diagnosis or treatment \(^{36}\).

Problems with patient identification were mentioned in six studies \(^{16,18,36,37,38,39}\). A Mexican study highlighted that four (3.1%) patients were mistaken for others \(^{37}\), and in Switzerland patients reported having been mistaken for other patients, called by the wrong name and receiving care not intended for them \(^{39}\).

Hand washing as a means to prevent HAI featured in four studies \(^{27,33,37,39}\). Patients were able to identify the lack of hand washing among staff and its importance \(^{27}\). However, in a Canadian study, few reported having asked staff to wash their hands \(^{38}\). In a Chinese study, 68% of patients were willing to remind staff to wash their hands \(^{40}\).

In the only Brazilian study \(^{18}\), omission of care was reported by three patients: one reported that no one monitored his reactions to the medication after reporting discomfort; another patient, in bed rest for 30 days, got up on her own and fell over the waste bins after unsuccessfully requesting nursing care; and in a third case, the nursing staff requested a medical evaluation after identifying increased blood pressure levels, to no avail. The incidents reported by patients were attributed to problems related to communication, high staff turnover and work overload.

Problems related to staff training and responsibility, staff management and workload, supervision, leadership and health team-related factors were mentioned by patients as potential triggers of incidents and adverse events \(^{32}\). Besides those aspects, issues related to material and structural resources in hospitals may interfere with patients’ perception of care quality \(^{16,20,32}\). Complaints about comfort and entertainment during hospitalization, food, parking and long waiting times were also identified \(^{16}\).

**Patients’ suggestions to prevent the occurrence of incidents and adverse events**

One of the key strategies to improve patient safety is to engage patients in recognizing risks and preventing harm \(^{38}\). A study carried out in England \(^{20}\) developed an action plan based on patients’ perspectives which contained some simple measures: changes in furniture arrangement in wards and rooms, and the provision of a container to store medication brought by patients from home, helping them manage administration. On the other hand, there were also more complex and costly initiatives, such as investigation of delays and staff training.
Four main topics were listed based on suggestions by patients to mitigate incidents and adverse events. The first and most common related to checking and reviewing treatment processes, managing risk and reviewing patient care, accounting for 43.2% of suggestions. These included attention to checklists, adequate supplies and facilities, and familiarity of staff with patients’ illnesses, laboratory results, allergies and information available before appointments and during care.

The second topic, staff professionalism and competence, was mentioned in 27.2% of the suggestions. They highlighted the importance of ensuring the necessary professional skills, including during staff holidays and leaves. Also stressed were the reduction of nursing turnover rates to ensure the flow of information and the importance of exchanging information among co-workers.

The third topic was the need for cooperation among patients, families and staff, mentioned in 21.1% of suggestions. Patients stressed that incidents can be prevented by listening to patients and family members about issues related to care and with clearer guidelines on admission and discharge. Also included in this topic was the need for empathy in treating patients. The last topic was related to improvement in environment safety (9.5%), including locking doors in the case of patients with impaired memory, checking the safety of beds and keeping the corridors clear to prevent patients from tripping.

**Discussion**

This review identified the main incidents, adverse events and contributing factors related to safety in the provision of hospital care from the perspective of patients, as well as variation in current terminology used in the examined studies.

Some terminologies adopted in the reviewed articles differ from those recommended by WHO in the IPCS, which made it difficult to compare results, especially in terms of frequency of occurrence. Variation in terminology and non-adoption of international taxonomy may interfere with organizational learning and the understanding and accurate reporting of incidents and adverse events. It should be noted that the term “error” was mentioned for medical error, diagnostic error, clinical error and error with harm. It is noteworthy that “error” is understood in this sense as an unintentional attitude, as a failure to execute a plan or the execution of an incorrect plan by all health care staff, not only the physician. Sometimes error was understood by patients as resulting from specific technical procedures and human error; in other cases it was related to tiredness and lack of organization. In the former interpretation error is attributed to a specific, one-off situation, regardless of the context, while in the latter it results from multiple variables in the system.

Problems related to stages of medication use stood out among incidents and adverse events reported by patients in hospital care, compared to other care processes. This may be related to previous experiences with medication use, which can positively influence self-care, contributing to the prevention of incidents and adverse events. Another important finding was issues related to communication, which play a key role in all aspects of health care quality. Communication-related problems were reported by patients as contributing factors to and potential triggers of incidents and adverse events.

The results of this review corroborate previous studies aimed at improving health care quality that highlighted problems related to the process of using medication and especially to communication. The latter is a relevant and legitimate concern given the evidence that communication failures are associated with the occurrence of adverse events. In turn, medication errors are among the most common incidents in health care, potentially happening in all stages of the health care process and sometimes also related to communication.

Other categories of incidents, adverse events and contributing factors related to the international patient safety goals such as infections, surgery-associated problems, falls, pressure injury and problems related to patient identification were also mentioned by patients, indicating their ability to identify unsafe care situations often highlighted in the relevant literature.

As for factors contributing to the occurrence of incidents and adverse events, the most cited were related to (i) staff, such as professional competence and physical and mental health; (ii) work pro-
cesses, such as communication failures; (iii) working environment, such as staff numbers and skills, workload and shifts; and (iv) organization and management, such as financial resources and restrictions and organizational structure 16,18,31,41,48.

It is essential to recognize, understand and mitigate the identified contributing factors, among which communication failures deserve special attention. Effective communication between staff and patients plays a key role in patient-centered care, favoring bonding between staff and patients, health literacy and education, and adherence to self-care and the proposed treatment. In this sense, patients and staff should make joint decisions, which encourages transparency and the appreciation of patients’ values, beliefs and choices during care 19.

Acknowledging that patients hold important and unique knowledge about their health status is essential for effective and safe treatment 29. Furthermore, knowledge and understanding of the experiences of patients and relatives when adverse events occur provide important information to strengthen the safety culture at the organizational level. Sharing those perspectives can encourage open communication and a change in patient safety culture, which should not be based on individual guilt or stigma, although deliberate neglect is unacceptable 30.

Patient involvement in care safety, whether related to their own care or future improvement of ongoing processes, is increasingly viewed as a means to reduce risks associated with health care, albeit dependent on the type of cooperation patients are able to establish with staff 38. Ideally, patients and family members involved in care become more active and engaged in discussions and decision making, including identifying unsafe situations before incidents occur, contributing to the safe use of medication based on their knowledge of the prescribed drugs and of possible side effects or adverse events, taking part in initiatives to control infections and promote hand washing, and encouraging open communication about complications and adverse events to favor a non-punitive culture and organizational learning 49.

Such benefits are hindered by fear and by patients being unaware that their attitude towards treatment can help reduce the risk of an incident or adverse event 26,41. Educational campaigns can minimize this knowledge gap and even create situations conducive to improved care 18,39. Similarly, individual traits of patients can influence the reporting of incidents, such as knowledge and beliefs about safety and emotional experiences with health care provision, including those related to demographics and also diseases, like stage and severity, symptoms, treatment plan 50 and previous experience with the occurrence of incidents and adverse events 26,31,50.

Compared to staff, patients generally have a different view of what incidents and adverse events are 9. They have a broader understanding of health care problems as they consider their entire care background, including the different levels of care and the household and community to which they belong, and are able to identify incidents and adverse events overlooked by staff 7. Care safety concerns reported by patients can be ignored by current incident and adverse event notification systems, which are mostly focused on notifications by staff. However, their point of view is essential to detect adverse events 11. The perspective of patients and relatives is valuable in many areas, including organizational environment design, care planning, notification of incidents and adverse events, and even analysis of root causes 51 and proposition of solutions.

This reveals the need for initiatives aimed at patient safety which also consider the opinion of patients, the main beneficiaries or victims of the health system. And important contribution in this sense would be to reformulate incident notification systems to include the views of patients, especially those who have experienced problems while using health care services. This should evidently be aligned with other educational strategies and notification systems for staff. A possible complementary measure is the creation of virtual communication spaces for patients to share their experiences, as it is likely that patient safety incidents reported by them in such spaces will not be picked up by other reporting means 27,36. Besides providing greater reach, social media and ombudsperson services have the advantage of being independent or outside the institutional environment.

The development of tools to identify relevant circumstances, incidents or adverse events from the viewpoint of patients is a challenge that requires cooperation between family members and staff. Thus, the literature stresses the importance of incorporating the opinion of patients in current information collection systems aimed at monitoring and ensuring patient safety 11,51. A further need is to acknowledge the emergence of new socio-psychological themes, focused on the cognitive and
emotional aspects of health care related to patients and relatives, as an issue of patient safety \textsuperscript{7} and, above all, patient-centered care \textsuperscript{19}.

**Limitations and contributions of the study**

Despite increasing attention to the subject since 2013 \textsuperscript{4} and the steady recognition over time of the active and critical role played by patients, the volume of selected studies fell short of expectations. Therefore, this review has limitations, some of which are inherent to its design of a literature review. Although broad terms were initially used, there were limitations related to inaccuracies in the search formula employed in the bibliographic databases and to the restricted inclusion of published scientific articles of free access or available through libraries, excluding gray literature, books or term papers, which may explain the limited number of articles selected for this review.

However, the expectation is to disclose here the state of the art regarding patient participation in ensuring and improving safe care in Brazil vis-à-vis international advances. Despite the existence of academic production and even government policy focused on patient safety, organizational culture, characteristics of the patient/staff relationship and the level of health literacy of the population are still barriers, even more so in Brazil. For patients to truly play a key role in the care process and be heard in decision-making there must be scope for them to voice their complaints without embarrassment or harm of any kind, especially in a society with such inequality in terms of socio-educational conditions and health care access, use, adequacy and effectiveness.

**Conclusions**

Patients are able to identify incidents and adverse events in health care, and their participation and contribution in initiatives aimed at improving health care quality and safety should be encouraged and their role increasingly appreciated.

Problems related to communication and use of medication were found to be the most reported by patients in this review. These results are in accordance with previous reviews \textsuperscript{9,10}. Issues related to The international patient safety goals were also identified in the reviewed studies, such as safe surgery, HAI, patient identification, falls and pressure injuries. Also reported were organizational factors, such as delays, incorrect diagnosis and poor care continuity; staff-related issues, such as work overload and poor listening to patients; and problems related to environment and structure of services, showing that patients’ perception of safety goes beyond that reported by staff.

This stresses once more the importance of considering the incidents, adverse events and contributing factors reported by patients and family members and combining them with those identified by staff to develop a plan to improve the quality of care. This is a step towards ensuring the key role of patients in this process at various levels.

This review stands out from previous ones for including studies in Portuguese and Spanish in the debate, expanding the range of countries and their respective cultural contexts. Moreover, it is worth noting the scarcity of research on the subject in Brazil, indicating the need for studies and initiatives to expand its insertion and engagement, plus regular data collection on patient safety and other aspects of care quality from the perspective of patients, family members and caregivers.

From an organizational point of view, despite the acknowledged relevance of the issue, current notification systems still do not seem capable of identifying all patients’ concerns about the quality of the care they receive. New arrangements in which patients play an active and leading role in care should be encouraged and developed to remedy this situation. Paradoxically, in the current context of lack of supplies and precarious hospital services in Brazil, giving voice to patients is both urgent and necessary to the founding principles of the Brazilian Unified National Health System – universality, equity, integrality and popular participation.
Contributors

V. C. F. L. Villar, S. C. M. Duarte and M. Martins participated in the conception, design, data analysis and interpretation, writing of the article and relevant critical review of intellectual content and approval of the final version for publication.

Additional informations

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Resumo

O objetivo foi revisar a literatura sobre os incidentes, eventos adversos e seus fatores contribuintes no cuidado hospitalar, descritos segundo a perspectiva do paciente. Foi realizada revisão em artigos publicados nas bases MEDLINE, Scopus e LILACS entre os anos de 2008 e 2019. Dentre 2.686 estudos inicialmente levantados, 167 foram pré-selecionados para leitura, 24 selecionados e categorizados de acordo com a análise temática de conteúdo. Na síntese das informações extraídas dos 24 artigos emergiram quatro categorias: terminologia usada para definir incidentes e eventos adversos, destacando-se diferentes nomenclaturas como erro e erro médico; incidentes e eventos adversos identificados pelos pacientes, familiares e cuidadores relacionados ao processo de medicação, cirurgia, infecções relacionadas à assistência à saúde, quedas e lesão por pressão; percepção do paciente quanto ao cuidado inseguro, destacando-se problemas relacionados à comunicação, higienização das mãos e identificação do paciente; sugestões dos pacientes para prevenir a ocorrência de incidentes e eventos adversos, incluindo treinamento de profissionais, elaboração de listas de verificação, escuta do paciente e adequação do ambiente. Pacientes foram capazes de identificar incidentes, eventos adversos e fatores contribuintes na prática do cuidado, que aliados às informações oriundas dos profissionais de saúde podem potencialmente contribuir para a prestação do cuidado em saúde mais seguro.

Segurança do Paciente; Assistência Centrada ao Paciente; Preferência do Paciente; Participação do Paciente

Resumen

El objetivo fue revisar la literatura sobre los incidentes, eventos adversos y factores que contribuyen al cuidado hospitalario, descritos según la perspectiva del paciente. Se realizó una revisión en artículos publicados en las bases MEDLINE, Scopus y LILACS entre los años de 2008 y 2019. Entre los 2.686 estudios inicialmente recabados, 167 fueron preseleccionados para la lectura, 24 seleccionados y categorizados de acuerdo con el análisis temático de contenido. En la síntesis de la información extraída de los 24 artículos emergieron cuatro categorías: terminología usada para definir incidentes y eventos adversos, destacándose diferentes nomenclaturas como error y error médico; incidentes y eventos adversos identificados por los pacientes, familiares y cuidadores, relacionados con el proceso de medicación, cirugía, infecciones relacionadas con la asistencia a la salud, caídas y lesión por presión; percepción del paciente respecto a los factores contribuyentes para el cuidado inseguro, destacándose problemas relacionados con la comunicación, higienización de las manos e identificación del paciente; sugerencias de los pacientes para prevenir la ocurrencia de incidentes y eventos adversos, incluyendo entrenamiento de profesionales, elaboración de listas de verificación, escucha del paciente y adecuación del ambiente. Los pacientes fueron capaces de identificar incidentes, eventos adversos y factores contribuyentes en la práctica del cuidado que aliados a la información procedente de los profesionales de salud pueden potencialmente contribuir a la prestación de un cuidado en salud más seguro.

Seguridad del Paciente; Atención Dirigida al Paciente; Prioridad del Paciente; Participación del Paciente

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