

Patients' Role in Their Own Safety —A Systematic Review of Patient Involvement in Safety

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Abstract

It is necessary to evaluate progress in the area of patient safety. However, although there has been an increase in number of quality and safety related studies have increased, the topics of patient involvement and patient safety are not automatically linked. The aim of this systematic review was to identify and evaluate the evidence contributed by studies of patient involvement in the provision of safe care. Inclusion criteria were studies undertaken to promote involvement in safety, covering patients' attitudes, unsafe and safe care, risk reduction and handover practices during discharge from hospital to primary care. The results revealed three themes: satisfaction with and need for knowledge about healthcare and the health system, sharing responsibility and accountability for safety and the need to overcome language barriers to prevent harm and error. In conclusion, there is an increased focus on the role of the patient in the provision of safe care. Existing evidence is related to medication rather than patients' capability and willingness to be involved. It is recommended that patient participation in the provision of safe care should be explored in relation to phenomena such as trust, responsibility, shared decision-making and powerlessness. It is also important to investigate the patient's role with respect to patient rights.

Keywords

Patient Involvement, Patient Safety, Systematic Review

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1. Introduction

Patient involvement in the provision of safe care is an area of growing policy and healthcare practice interest, but the agendas are not linked. Recent developments have resulted in calls for more active patient involvement in safety [1]. An empirical approach to the World Health Organization (WHO [2]) patient safety model revealed that of the 23 components, only a few were achieved in the context of depressed elderly patients [3]. Low quality and lack of safety were found due to psychological distress, stress and fatigue, the absence of involvement in decision-making, misdiagnosis, sleep problems as a result of harm from medical error and the poor physical state of patients suffering from depression [3]. Older patients with depression and those who have received treatment for a longer period reported a lack of shared decision-making [4] [5].

Patient involvement is a complex phenomenon for which no single definition exists and various terms such as patient collaboration, patient participation, partnership, patient empowerment and patient-centred care are used interchangeably [6]. Findings regarding patient involvement in the provision of safe care vary and should be made more consistent in order to better understand the different aspects of the phenomenon. It is being debated as to whether patients should have a role in their own safety [1]. The question of whether patients want to participate has also been raised [6]. Lyon [7] emphasised that patients can contribute information about the progression of their symptoms and their experiences of treatment, thus leading to a better outcome. In addition, if a sign or symptom changes, the patient is the first link in the chain to experience and have the opportunity to communicate it. The potential role of patient involvement in their own care is not well described. A recent review of patient participation revealed several patient-related factors such as acceptance of the new role, lack of medical knowledge, lack of confidence, comorbidity, and various sociodemographic parameters that affected their willingness to participate or be involved in their healthcare process [6]. Borgsteede *et al.* [8] focused on patients' need for information about medication when being discharged from hospital, emphasizing its importance to the individual patient.

The WHO recognized the necessity of patient involvement for strengthening the voice of patients as advocates for safer healthcare [2]. The WHO Alliance for Patient Safety also emphasized that the patients' family members could play an important role in the improvement of care. According to the WHO [9], risk and uncertainty are constant companions. In the study by Hansen *et al.* [10], the patients reported that sensitive and supportive healthcare professionals who paid attention, listened to and believed their experiences were very important. Various factors have been described as influencing patient involvement in decision-making process, the treatment process and evaluating the service aimed at improving the healthcare system [6]. A review by Brennan *et al.* [11] focused on trust in the healthcare provider-patient relationship as it can affect the quality of care. Patients' experiences of trust are dependent on the nurses' knowledge, level of commitment and safety [12]. An additional factor that influences patient safety is teamwork. Manser [13] provided an overview of teamwork components relevant to the quality and safety of patient care, including collaboration characterized by respect and trust. The author highlighted aspects such as shared mental models (*i.e.*, the strength of shared goals and perceptions as well as understanding of team structure and team roles); coordination (*i.e.*, increased information exchange and planning in critical situations); communication (*i.e.*, openness and quality of communication, *e.g.* team debriefing); and leadership (*i.e.*, leadership style, promoting participation in decision-making). This review focuses on studies undertaken to promote patient involvement in safety, covering patients' attitudes, unsafe and safe care, risk reduction and handover practices during discharge from hospital to primary care are in focus.

Aim

The aim of this systematic review was to identify and evaluate the evidence contributed by studies of patient involvement in the provision of safe care. The review questions addressed were: What is the evidence of patient involvement in their own safety? and what is patients' role in provision of safe care?

2. Methods

2.1. Search Methods

The first author recruited a specialized librarian to discuss the keywords to be used in various databases in order to identify peer-reviewed articles on the topic of interest. The following keywords were selected: *consumer participation/or patient participation and safety management/or patient safety* in various combinations. In addition,

the term *qualitative* was used to specify the design of articles. The inclusion and exclusion criteria are listed in **Table 1**. Initially four electronic databases were used, after which the results were discussed and the various hits compared by the authors (**Table 2**). The first search covered the period from February 2005 to February 2015. In the second stage an additional screening was conducted from February to April 2015, to ensure that all articles that met the criteria were included. A manual search of references in the selected articles was made to identify additional studies (**Figure 1**, [14] [15]).

2.2. Quality Appraisal

In order to evaluate the quality of the included articles ($n = 15$), as well as the degree to which they mirrored the aim of this systematic review and addressed the review questions, they were examined by means of an academic structuring of aspects, such as, aim, research questions, methods, results and conclusion to evaluate the quality of the articles mirroring the aim of this study and addressed review questions [16] **Table 3**.

2.3. Analysis and Synthesis of the Included Articles

The two authors individually conducted a content analysis on the articles, which was followed by discussions in order to achieve consensus and strengthen validity. Interpretation of the content of took place through a process of iterative reading possible themes were discussed on a descriptive level. During the second stage of the analysis the authors' spent time discussing and comparing the evidence, which resulted in a preliminary synthesis of patients' role and involvement in their own safety [17]. At the latent level, the authors reflected on and abstracted the content to produce a new interpretation that goes beyond the original studies. The data synthesis is described in **Table 4**.

3. Results

Of the included papers, 15 were qualitative studies and one had a mixed design [18]–[32]. The articles employed various data analysis approaches such as narrative, thematic coding and qualitative content analysis. Two of the studies used software for analysis. The included subjects varied between 10 and 90 patients. There were limitations reported in relation to generalizability, the diagnosis of patients, hospital versus community settings, sampling technique and small sample size.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria

Peer-reviewed articles published between February 2005 and February 2015

English language

Qualitative and mixed design

The term patient safety (including harm and risk) in the title and/or abstract

Exclusion criteria

Healthcare professionals' perspective

Quantitative studies

Table 2. Electronic database search outcomes.

	Results
Ovid MEDLINER	215
Cinahl	279
Cochrane Library	38
Proquest	49

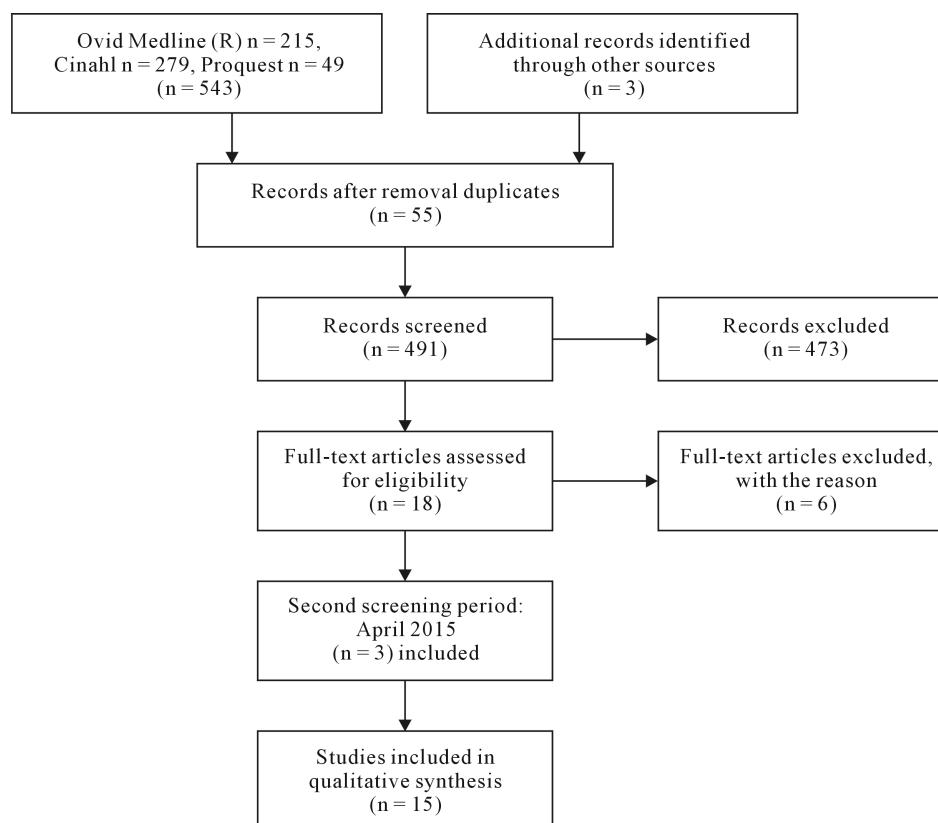


Figure 1. Flowchart of search outcomes and selection process of articles on patient involvement in their own safety (PRISMA [15]).

Table 3. Summary of the included articles on patient involvement in their own safety.

Author country year	Aim and research questions	Subjects and study setting	Method/design data-collection	Data analysis	Trustworthiness (validity/reliability)
1) Davis <i>et al.</i> (2011) UK	To evaluate patients' attitudes towards a video and leaflet aimed at encouraging patient involvement in safety-related behaviours	n = 80 patients (study 1) n = 80 patients (study 2)	Mixed method	Content analysis	In relation to interrater reliability, the researchers met after the independent analysis to ensure consensus on the themes
2) Flink <i>et al.</i> (2012) SWEDEN	To explore patients' experiences of and preferences for participation.	n = 90 n = 53 individual interviews n = 37 focus group interviews	Qualitative Individual interviews, Focus group interviews	Qualitative secondary analysis.	Linguistic misinterpretation. Limitations in generalizability because of patients with chronic conditions
3) Flink <i>et al.</i> (2012) SWEDEN	To improve the knowledge and understanding of patients' perspectives on their participation in handover	n = 23	Qualitative	Inductive qualitative content analysis	Limitations related to generalizability
4) Gabitowa <i>et al.</i> (2014) USA	To evaluate the patient navigation program in a safety-net hospital breast clinic by assessing its impact on patients' experiences of cancer care	n = 16 patients,	Qualitative Individual interviews	Software Atlas.ti for coding and analysis	Limitations related to generalizability
5) Groene <i>et al.</i> (2012) UK	To explore handover practices at discharge and to focus on the patients' role in handovers and on the potential additional risk for vulnerable patients	n = 12 patients	Qualitative	ATLAS.ti software package	Limitations are addressed; hospital settings that may not be applicable to the general practice setting

Continued

6) Hernan <i>et al.</i> (2014) AUSTRALIA	To explore patients' and carers' perceptions of safety in rural general practice	n = 26 patients and carers	Qualitative approach, focus group interview	Narrative analysis	Limitations are addressed
7) Hrisos & Thomson (2013) UK	To explore from the perspectives of both patients and frontline healthcare staff, the potential consequences of a patient-mediated intervention as a way of improving safety through improvement through the involvement of patients from the perspectives of both patients and frontline healthcare staff.	n = 16, patients n = 4, relatives	Qualitative study, semi-structured interviews	NVIVO 8.	The findings cannot be generalized
8) Bishop & Macdonald (2014) UK	To describe patient involvement in patient safety practices	n = 10	Qualitative approach, focus group interview	Thematic analysis	The findings cannot be generalized
9) Martin <i>et al.</i> (2012) DENMARK	To investigate existing practices for patient involvement in patient safety, as well as opportunities for and barriers to further involvement	n = 25	Ethnographic methodology. Qualitative study	Nvivo for thematic coding	The departments involved received a short report or presentation with their own results and commented on them to refine the material and enhance validity
10) Ocloo (2010) UK	To investigate the occurrence of medical harm and the construction of patient safety reforms in order to increase awareness of alternative narratives about issues of power and accountability	n = 21 14 groups	Qualitative study	Narrative analysis	Not reported.
11) Porter & Lasiter (2008) COLUMBIA	To describe the attitudes of older housebound women related to the risk of intrusion	n = 32 participants	Descriptive phenomenological method	Descriptive analysis	Illustrative examples are included
12) Pinto <i>et al.</i> (2013) UK	To explore patients' attitudes towards the PINK video, a patient education video aimed at encouraging hospital patients' involvement in safety-relevant behaviours	n = 36, 20 - 79 years, 18 females 18 males	Qualitative semi-structured interviews. Field notes	Content analysis	In order to access the generalizability of the findings further research on attitudes towards the video is needed in different settings with a variety of patient groups
13) Rise <i>et al.</i> (2014) NORWAY	To explore how mental health service users perceive the relationship between safe care on the one hand and increased influence and decision-making on the other	n = 15 patients	Qualitative study	Not reported	Not reported
14) Schwappach & Wernli (2010) SWITZERLAND	To assess chemotherapy patients' perceptions of safety and their attitudes towards participation in error-prevention strategies	n = 30 patients	Qualitative study. Semi-structured interviews	Content analysis	Small sample size. Restricted generalizability. The authors chose this group of patients to minimize hypothetical bias that might explain observed differences between patients' attitudes towards involvement in error-prevention strategies and their actual behaviour
15) Vaismoradi <i>et al.</i> (2011)	To explore patients' understandings and feelings of safety during hospitalization	n = 19 patients	Qualitative	Thematic analysis	Peer checking was performed to strengthen the credibility of the data analysis. Dependability was achieved by an audit trail from the start of the data collection until the formulation of the themes.

Table 4. Patient safety.

Themes	Satisfaction with and need for knowledge about healthcare and the health system	Sharing responsibility and accountability for safety	The need to overcome language barriers to prevent harm and error
Subthemes	Increasing trust and positive attitudes Need for support, hope and predictability	Responsibility and information about medication Patients' active role in their own safety Checking professional accountability is difficult	Risk of medical harm and feelings of vulnerability Handling mistakes and adverse events caused by lack of knowledge and harm

Characteristics of patient involvement in safety can be described by three themes: *satisfaction with and need for knowledge about healthcare and the health system*; *sharing responsibility and accountability for patient safety* and *the need to overcome language barriers to prevent harm and error*. The first theme was based on two sub-themes; increasing trust and positive attitudes and need for support, hope and predictability. The second theme had three sub-themes; responsibility and information about medication, patients' active role in their own safety and checking professional accountability was embarrassing. Finally, the third theme was constructed on the basis of two sub-themes; risk of medical harm and feelings of vulnerability and Handling mistakes and adverse events caused by lack of knowledge and harm.

3.1. Satisfaction with and Need for Knowledge about Healthcare and the Health System

According to Martin *et al.* [26], most of the participants expressed overall satisfaction with the health system and considered safety to be high, despite the fact that almost everybody reported adverse events (diagnostic delay, hospital-acquired infections, medication errors). Although a few emphasised that they had become more observant, particularly with regard to the processes associated with the adverse events, most had confidence in the individual healthcare professional.

In three studies the need for greater knowledge about healthcare was reported [3] [25] [29]. Pinto *et al.* [29] explained that the participants thought that a video could be an important educational tool for increasing patients' knowledge of the role they can play during hospitalization. In the study by Bishop and Macdonald [25], the participants reported that they did not know enough about their own treatment while hospitalized. In some cases this was due to the fact that healthcare professionals did not share important knowledge, which made the participants feel ignorant about their care and mere treatment projects. Rise *et al.* [30] reported that the participants described participation in safety as a learning process with limited knowledge and feelings of stress at the beginning of therapy, but progressing by means of additional experiences to "expert status" level.

3.1.1. Increasing Trust and Positive Attitudes

Six studies demonstrated the importance of increasing trust and positive attitudes [20] [23] [24] [26] [31] [32]. Schwappach and Werni [31] stated that patients overwhelmingly reported that their participation in error prevention did not erode trust or negatively affect relationships with their caregivers. Although in general professionals expressed trust and confidence in coordinators' ability to communicate health-related information to patients, one of them noted some limitations in their knowledge when working with complicated cases. Hernan *et al.* [23] revealed that continuity of care and trust in the physician-patient relationship reduced the perception of risk. The participants described the characteristics of general practitioners (GPs) that contributed to a sense of trust, which included confidence in their clinical competence and their personal knowledge of the patient. Vaismoradi *et al.* [32] found that nurses who had frequent contact with patients and their presence in patients' rooms helped to build a trustful relationship and assured the patients that they would receive the necessary care. When the participants were asked to describe their understanding of patient safety, they defined it as caring for patients' dignity and well-being. They mentioned that they expected healthcare professionals, especially nurses, to place a high value on their dignity and well-being and that they would not be neglected. In addition, patient safety was portrayed as being loved and respected by healthcare professionals. Flink *et al.* [19] reported that the participants claimed that trust in the healthcare professionals was important for patients' willingness to commu-

nicate, as they limited the information they shared with healthcare professionals who they distrusted or felt uncomfortable with them. The attitude of the healthcare professionals was also important for patients' willingness to participate in handovers. According to Martin *et al.* [26], many patients associated safety with a feeling of being in "good hands", respectful communication and a good relationship with healthcare professionals, rather than with factual knowledge of potential errors and hazards. Hrisos and Thomson [24] reported that the participants often commented that they "had to put their trust" in those providing their care and "you put your life in their hands" when you go into hospital. While there was an element of "hope" in this, there was also a general expectation that healthcare professionals, "know what they are supposed to be doing" and a common assumption that they always did what they were supposed to do, for example, washing their hands properly, knowing that the leg they were about to operate on is the correct one, or administering the correct medications.

3.1.2. Need for Support, Hope and Predictability

Two studies revealed that that every event that disappointed patients or reduced their hope of recovery endangered their feeling of safety and led to a need for support, especially in phases of serious illness [30] [32]. Vaismoradi *et al.* [32] stated that the participants' hope of recovering diminished, resulting in feeling of being unsafe during hospitalization. However, patients felt safe when nurses cared about their concerns and took them seriously. Rise *et al.* [30] described a need for predictable contacts with professionals who had at least some knowledge about their situation and needs. Participants described it as demanding and difficult to have to repeatedly relay the same information.

3.2. Sharing Responsibility and Accountability for Safety

Four studies reported the value of sharing responsibility for safety between patients and healthcare professionals. Flink *et al.* [20] revealed that the patients assumed responsibility for establishing contact with the new care unit as well as the responsibility for collecting, storing and handing over essential information about their care, such as medication lists and discharge notes. Martin *et al.* [26] found that many patients claimed that all patients have a responsibility—within reason and depending on individual capability and health—to do everything within their power to get well, but they also stressed that patient safety is the responsibility of the healthcare professionals, not the patient. However, both Martin *et al.* [26] and Rise *et al.* [30] recommended that professionals should assume some or all of responsibility for these areas when the patient feels unable to do so. According to Bishop and Macdonald [25], sharing responsibility highlighted the behaviours or actions the participants took while hospitalized to ensure that they felt safe. Rise *et al.* [30] revealed that in difficult illness phases and crises the participants expressed a wish to share responsibility with professionals for various things, such as their finances, filling in forms, making phone calls and decision-making, with professionals.

3.2.1. Responsibility and Information about Medication

Three studies reported that the participants wanted information about their medication [20] [23] [27]. Hernan *et al.* [23] described the need for information about the names of the drugs, for what they were prescribed and how they should be used. Flink *et al.* [20] revealed that patients were discharged with unclear or insufficient knowledge of how best to handle their medications or without a new or updated medication list. Martin *et al.* [26] showed that many of the participants brought a medication list, were familiar with their medical record and searched for additional knowledge about the treatment from other sources, while others had a fairly passive stance. Hernan *et al.* [23] explained that participants lacked appreciation of the systemic nature of medical error and as a result, placed sole responsibility for errors on the GP.

3.2.2. Patients' Active Role in Their Own Safety

Two studies emphasized patients' active role [20] [23]. Flink *et al.* [20] explained that patients who functioned as key actors perceived their active involvement as necessary for continuity of care. These patients had either learned from past experiences that little or no information was transferred unless they did it themselves, or perceived that healthcare professionals expected them to assume the initiative and play an active role during their handover. According to Flink *et al.* [19], little or no information was exchanged between the emergency ward and primary healthcare unless patients themselves conveyed it to ensure continuity of care. At their discharge patients specified which primary healthcare provider should receive their handover information, and actively

took it upon themselves to ensure continuity of care between their healthcare providers. Groene *et al.* [22] characterised the patient's role in the discharge handover as passive, whereby patients are handed their referral or discharge letters and instructed to deliver them to their community GP. Patients did not perceive this role as positive and did not consider that the information belonged to them as they were unable to make sense of the technical language, thus were not empowered to assess or add to the information.

3.2.3. Checking Professional Accountability Is Difficult

Two studies stated that the participants often find professional behaviours embarrassing [24] [29]. Pinto *et al.* [29] added that certain behaviours could ruin the patients' relationship with staff. Patients expressed their reluctance to question healthcare professionals on, for example, their hand hygiene behaviours and remained unwilling to do so after watching a video to promote questioning staff. The same was stated by Hrisos and Thomson [24], who revealed that checking to ensure that professionals were doing their job correctly appeared insulting. These beliefs were also evident in the accounts of healthcare professionals speaking of their experience as patients and relatives. Asking healthcare professionals if they had washed their hands was particularly problematic, with most patients stating that this was something they probably or definitely would not do.

3.3. Need to Overcome Language Barriers to Prevent Harm and Errors

Five studies reported the need to overcome language barriers [21] [22] [24] [25] [31]. Schwappach and Werni [31] pointed out the benefits of assertive communication and constructive listening skills, revealing that the participants considered the coordinators influenced their ability to ask questions in a positive way. Irrespective of their first language, many patients reported difficulty understanding medical terminology and both patients and professionals stated that the team coordinator's role in clarifying medical terminology and speaking in a clear, understandable way was one of the most valuable aspects of the navigator programme. According to Groene *et al.* [22], patients who experience ill health, language barriers and low health literacy may be unable to provide information about their medications, or inform professionals about allergies and possible drug reactions. According to Hrisos and Thomson [24], the participants and their relatives welcomed the opportunity to ask questions have their concerns addressed, as it provided reassurance, a better understanding of what was happening to them and what to expect. According to Bishop and Macdonald [25], stated that a relationship with healthcare professionals was created with healthcare professionals when the patient perceived them as taking time to listen to them. Some participants described this as being friendly with one another, while others expressed that it showed respect for the patient as a person. Patients and nursing staff considered the act of building a relationship an important step in ensuring patient involvement in their care. Several participants stated that healthcare professionals, especially nurses, were too busy to talk or answer questions. According to Gabirtova and Burke [21], communication requires constructive listening skills that are hypothesized as being associated with healthcare empowerment. Hence many of the participants felt that the coordinators enhanced their ability to ask questions in a positive way.

3.3.1. Risk of Medical Harm and Feelings of Vulnerability

Three studies highlighted the participants' perceptions of the need for a self-help network to challenge the dominant medical perspectives [23] [24] [27]. Ocloo *et al.* [27] stated that the participants who wished for a self-help network wanted to develop an association that challenged the dominant medical perspectives that they viewed as working to their detriment. This standpoint about the power of the medical profession and a focus on accountability concurs with other research. Hernan *et al.* [23] revealed that the participants described feelings of vulnerability in their experiences of care. Many suffered from multiple chronic conditions and therefore considered themselves at greater risk of medical or psychological harm. Reported medical harm included misdiagnosis, treatment delays, not adhering to standard care procedures, and medical error. The psychological harm experienced by some participants included verbal abuse, disrespectful or dehumanising behaviours or practices such as lack of eye contact, and dismissive, rude or aggressive interactions. The power dynamics between the patient and the doctor also contributed to the patients' vulnerability. Hrisos and Thomson [24] revealed many patients have a real fear of being rebuffed or chastised, which was described as the main barrier to speaking up. This vulnerability that patients experienced while in hospital intensifies the heightened sensitivity about the fear that their care might be compromised. Patients were afraid that healthcare professionals would not look after them as

well as they had done before if upset by patients or her/his relatives. The participants struggled to explain this and were eager to clarify that they did not really believe that staff would do anything so inappropriate as to cause them harm.

3.3.2. Handling Mistakes and Adverse Events Caused by Lack of Knowledge and Harm

Four studies stated that the participants forgave mistakes and errors [23] [27] [29] [31]. Ocloo [27] reported that there was a deep-seated anger about the way that healthcare professionals and organisations concealed harm to patients, treating the harmed patient as the problem. This situation was compounded by the failure of a range of external organisations to provide an independent investigation into the issues. Some of the participants described their anguish about being harmed both by the medical professional and the systems responsible for regulating it and protecting patients. Schwappach and Werni [31] revealed that some of the participants had experienced errors and adverse events. The meaning of adverse events was unintended incidents with actual or potential harm for which the distinction between error and complication was not possible. Most of these reports related to incorrect or forgotten medications and doses, as well as complications, problematic implantation and the failure of physicians to communicate medication changes to nurses. Despite these experiences, patients reported feeling safe and were relatively unconcerned about errors. Hernan *et al.* [23] pointed out that some participants considered mistakes or errors in their care as “normal”. They expressed understanding and sympathy for the GP’s situation and considered mistakes as part of being human. Many viewed the GP as an ordinary person who is not “god-like” or omnipotent. However, the participants reported the need for an explanation of what went wrong and why. They described apology as the most effective way for patients to recover and move on from an incident. Pinto *et al.* [29] revealed that many participants reported that encouraging patients to speak up increased health-related awareness. Rise *et al.* [30] demonstrated that most of the participants regarded communication as an important strategy for preventing errors and stated that being proactive, asking questions, communicating with staff, reporting symptoms to clinicians and describing any deviations from routines are contributions that patients can make, depending on their physical and psychological well-being.

4. Discussion

Of the papers 15 were synthesis and all of the studies used a qualitative approach with the exception of one that applied a mixed method. These studies exhibit considerable heterogeneity in terms of patients’ experiences related to patient safety. The studies were analysed by means of content analysis [17]. The main finding of this review was the importance of phenomena such as, responsibility, trust, powerlessness, and shared decision-making, which constitute the core features that increase patients’ involvement in their own safety.

Evidence of the patient’s role in patient safety is scarce, thus more research is required. Recently, other authors have studied differing perspectives on patient involvement in their own safety. Entwistle ([33], p. 82) argued that relying on patients to be involved in checking the care they receive from health professionals is neither an effective nor an appropriate strategy for promoting patient safety. Furthermore, there are important differences between relying on patients to monitor their healthcare delivery to ensure their safety and involving them in their care while making efforts to improve their safety.

Increasing patients’ role in the management of their own safety and prevention of adverse healthcare events has been suggested by the WHO [9]. The key concepts of existing patient safety legislation are: information, involvement and empowerment/support. Two systematic reviews [34] [35] indicated that in general, patients are in favour of playing a role in safety, but are also seen as passive in that they consider safety to be a professional responsibility. In addition, patients stated that they found it easier to challenge nurses than physicians. An increased focus on developing patient safety management is necessary, especially for chronically ill patients. However, there are differences in patients’ capability and willingness to be involved due to their diagnosis, illness severity and previous experiences of powerlessness in decision-making. It also requires trust in the relationship between the healthcare professional and the patient. Rørtveit *et al.* [12] explored the phenomenon of trust from the patient perspective and found attitudes related to trust, indicating that trust is fundamental and existential, as well as experiences of trust, concerning how trust can be sensed. The patient-nurse relationship requires the qualities that create trust. A trustful confidential relationship that includes being invited to participate in a dialogue that is interpretative in character rather than just receiving information about different treatments can improve safety. Thus, an interpretative role will increase patients’ involvement in their care. However, pa-

tients' experiences of trust in nursing are dependent on the nurses' knowledge, level of commitment to creating and developing the relationship as well as on contextual issues.

Information will help patients to understand how they can be active in their role and even more importantly, how to handle uncertainties. Hansen *et al.* [10] explored the phenomenon of uncertainty from the patient perspective and concluded that it comprised two main areas, the first based on three themes: explaining, feeling and facing uncertainty. The second main area suggested intervention strategies consisting of three themes: organizing the patient trajectory through the healthcare system, supporting patients by means of relationships and providing knowledge through clear and accurate communication. Insight, confidence and supporting the patients' feeling of control rather than dealing with uncertainty are not only of importance for patients but also for healthcare professionals.

Several strategies must be developed to promote patient involvement such as patient safety-oriented interventions and educating patients about safety as the latter receive little practical support to carry out the recommended activities [36]. The main focus of the interventions should be encouraging patients to become involved in shared decision-making. However, sharing decision-making with patients requires adequate information and knowledge. Active involvement in decision-making may increase the effectiveness of the treatment [37]-[40]. Hall [34] identified interventions aimed at encouraging patient involvement by monitoring and ensuring safe delivery of treatment by self-management. Strengthening patient involvement in evidence-based decision-making will increase patient empowerment.

Limitations

The strength of this paper is the search and inclusion process, which included developing of a search strategy with a specialised librarian and literature expert and the use of two reviewers. The review is limited to studies that examine patients' involvement and role in their own safety. An additional limitation is that studies published in languages other than English were excluded.

5. Conclusion

This updated review indicates an increased body of research on patients' involvement in their own safety. Nevertheless, such studies remain scarce. Existing evidence concerns medication and informed treatment choices rather than patients' capability and willingness to be involved in decision-making. It is recommended that patient involvement in their own patient safety should be explored by means of core phenomena such as trust, responsibility, shared decision-making and powerlessness. It is also important to explore the patient role with respect to patient rights.

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Competing Interest

The author's declare that there are no conflicts of interest.

Contributors

The study was designed by E.S. E.S. coordinated the research. A.L.H. and E.S. participated in the data analysis and interpretation. The report was written by E.S. and A.L.H.

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