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Patient Engagement In Health Care Safety: An Overview Of Mixed-Quality Evidence

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Abstract

Patients and caregivers play a central role in health care safety in the hospital, ambulatory care setting, and community. Despite this, interventions to promote patient engagement in safety are still underexplored. We conducted an overview of review articles on patient engagement interventions in safety to examine the current state of the evidence. Of the 2,795 references we evaluated, 52 articles met our full-text inclusion criteria for synthesis in 2018. We identified robust evidence supporting patients' self-management of anticoagulation medications and mixed-quality evidence supporting patient engagement in medication and chronic disease self-management, adverse event reporting, and medical record accuracy. Promising modes of patient engagement in safety, such as anticoagulation management and patient portal access, are not widely implemented. We discuss major implementation priorities and propose directions for future research and policy to enhance patient partnership within safety efforts.

Since the publication of the patient safety report *To Err Is Human* in 1999,¹ the role of patient and family caregivers within the safety of health care has grown in prominence. In

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parallel, health care is increasingly delivered in the outpatient setting with shorter inpatient stays, more frequent care transitions between the hospital and other care sites, growing shared responsibility among members of patient care teams, and increasingly complex management of chronic diseases in the home and community.² In the hospital, patients are under continual observation. In the ambulatory setting, patients, families, and caregivers have more frequent opportunities to promote safety in partnership with a multidisciplinary care team.

Patient engagement is the involvement of patients, families, and caregivers in improving health care and health care safety.³ Although some editorials on patient engagement have questioned whether patients wish to be engaged,⁴ patients have overwhelmingly expressed a desire for some form of engagement in a diverse range of health care settings. However, it is important to acknowledge that patients' preferences, self-efficacy, and power dynamics may impede engagement in safety initiatives.⁵ There have been mandates to implement and evaluate patient engagement in safety from the Joint Commission, the Agency for Healthcare Research and Quality, and the World Health Organization.⁶⁻⁹ The Department of Health and Human Services lists patient engagement as a key strategy in its national action plan for the prevention of adverse drug events.¹⁰ Patient and family engagement also appeals to principles of equity, by recognizing patients as valued partners in developing safer health care systems.¹¹

Examples of patients' being engaged in the safety of their own care include monitoring and self-administration of medications, alerting care teams to concerning symptoms, and reporting adverse events.¹² As the loci of continuity during care transitions and the primary managers of chronic diseases in the home and community, patients and caregivers can identify disruptions during care transitions and alert care providers to events leading to preventable harm that might otherwise go unrecognized. Patients and caregivers can also participate in hospital safety initiatives or advisory councils as a means of engaging at the level of the health care organization.

In this era of patient-centered care, health care leaders are in search of efficacious strategies to involve patients and families in health care safety. However, the evidence base to guide engagement has been limited. A 2010 systematic review by Jill Hall and coauthors found poor-quality evidence that patient engagement can improve safety through self-monitoring of anticoagulation medication, designing patient educational materials, and participating in self-management with individualized teaching or counseling.¹³ We sought to update this review to describe the current state of the science of patient engagement within health care safety. Given that there has been an explosion of research on patient engagement within safety over the past decade, we conducted an overview of review articles to provide a high-level scan of the literature. This article highlights evidence-based strategies to support patient and family engagement in promoting safe care in the hospital, clinic, pharmacy, home, and community and identifies gaps to inform patient safety research and policy agendas.

Study Data And Methods

SEARCH STRATEGY

We adapted the search concepts used in the review by Hall and coauthors¹³ to create two content areas for our search strategy: patient engagement and safety. We examined search strategies of several previous systematic reviews involving patient engagement and safety topics¹⁴⁻¹⁶ to add relevant terms to our search strategy. Because we were conducting an overview of reviews and wanted to capture a variety of review article types, we added a “review methodology” component to the search. We developed the final search strategy in collaboration with the clinical librarian on the team using an iterative process to test individual search terms, including keywords and controlled vocabulary (such as MeSH and Emtree terms) for each search concept. We developed the search for use in PubMed and then applied it to other databases, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and review-of-reviews methodological guidelines.^{17,18} A second librarian external to the study team reviewed the final search strategy using the Peer Review of Electronic Search Strategy (PRESS) guidelines.¹⁹ The databases searched on February 13, 2018, were PubMed, Embase, CINAHL, PsycINFO, and the Cochrane Library. The search strategies are listed in online appendix exhibit A1.²⁰ The review protocol was registered in PROSPERO (ID: 2017 CRD42017071461), an international database of systematic reviews.

STUDY SELECTION

Four independent reviewers (all among the authors) independently performed screening, as follows. Each article’s record was uploaded to DistillerSR, a software program, to manage the review process. All records retrieved through searches underwent title and abstract screening by the study team. All records tagged by one reviewer as potentially relevant, as well as those for which abstracts were unavailable, were screened for inclusion at the full-text level. To be included, articles had to be reviews (systematic, literature, narrative, or scoping) that involved patient engagement interventions and reported patient safety outcomes. Studies were excluded if they were not related to patient engagement; did not focus on safety outcomes; were primary research (that is, not reviews); reported patient engagement in research (not clinical care); were conference posters or abstracts; were not in English; or had been published outside the period of 2007–17, as the inclusion terms for the review by Hall and coauthors¹³ ended in July 2008, by which time some 2007 references might not have been indexed. Full inclusion and exclusion criteria are available in appendix exhibit A2.²⁰ Both reviewers had to agree that a paper did not meet inclusion criteria in order to be excluded. When disagreements occurred, consensus was achieved through discussion between the two reviewers or an additional team member.

DATA EXTRACTION

We created a standardized form to extract the number of final studies included in each review; characteristics of the patient engagement intervention; characteristics of patient safety represented by the outcome; the level of harm of the outcome; an assessment of the quality of the review using the criteria specified in AMSTAR,²¹ a validated tool that assesses the methodological quality of systematic reviews on a scale of 0 (low quality) to 11 (high

quality); and a summary of the review's conclusions. Three reviewers completed data extraction, with two reviewers available to resolve discrepancies.

LIMITATIONS

This overview had several limitations. First, it did not capture all published work on patient engagement in safety. We focused on published reviews and therefore excluded single trials that might have discussed novel means of patient engagement in safety.

Second, as this was a conceptual overview with heterogeneous study outcomes, we performed a narrative synthesis, not a meta-analysis.

Third, we objectively rated the quality level of each review article, but the quality levels of all primary data were not available.

Fourth, few of our included reviews contained demographic summaries of the patients who were engaged in these studies. Thus, historically underserved patients such as members of racial and ethnic minority groups, people with limited health literacy or English proficiency, and those facing socioeconomic barriers might not have been represented.

Study Results

The database searches yielded 2,795 references after removal of duplicates. The abstract screening excluded 2,579 of these articles. Of the 216 articles that remained for full-text review, we excluded 164. The most common reasons for exclusion were that the article was not a review, the review did not report a patient engagement intervention or patient safety outcome, the review was published outside of the publication date range, the review was not in English, or the review was a conference poster. The final analysis included fifty-two reviews meeting inclusion criteria (appendix exhibit A3).²⁰ The mean AMSTAR quality rating was 4.7, corresponding with medium quality. Eleven reviews were high quality, twenty-four medium quality, and seventeen low quality. Exhibit 1 presents an overview of patient safety targets, engagement interventions, and summaries of evidence findings with quality levels (additional study details are in appendix exhibit A4).²⁰

The fifty-two included reviews encompassed a broad range of safety topics. We grouped the reviews into categories of safety targets, ordered by review quality: anticoagulation management (seventeen articles); hypoglycemia in management of type 1 diabetes (three); medication safety, which included medication adherence (four), patient or caregiver reports of an adverse event related to medication (nine), and medication administration errors (five); administrative errors (four); diagnostic errors (one); malpractice lawsuits (one); hospital readmissions (six); health care-associated infections (four); and pressure ulcers (one). Some studies addressed multiple outcomes.

ANTICOAGULATION MANAGEMENT

Seventeen reviews (six of high, six of medium, and five of low quality) assessed the evidence for patient engagement in self-monitoring and titrating warfarin doses for anticoagulation. These studies, whether assessing self-monitoring alone or in combination

with patient-directed dose adjustment, consistently found statistically significant reductions in thromboembolic events and mortality compared to usual care (appendix exhibit A5, articles 1–17).²⁰ Results for reduction of bleeding events were mixed.

HYPOGLYCEMIA IN DIABETES MANAGEMENT

Three reviews described mixed results for the role of patient self-management to prevent hypoglycemia in diabetes. One high-quality review reported that digital self-management apps or other tools to promote self-management were associated with improved diabetic control but with a mixed effect on preventing hypoglycemia, based on heterogeneous studies with high risk for bias (appendix exhibit A6, article 2).²⁰ Another high-quality review on interventions to promote patient activation—such as promoting increased knowledge, confidence, or skills for disease self-management—found improved diabetic quality outcomes but not hypoglycemia or mortality (appendix exhibit A6, article 1).²⁰ One low-quality review reported that patient education and training in self-management prevented hypoglycemia and diabetic ketoacidosis in patients with type 1 diabetes (appendix exhibit A6, article 3).²⁰

MEDICATION SAFETY: ADHERENCE, PHARMACOVIGILANCE, AND ADMINISTRATION

Four reviews, ranging in quality from high to low, discussed patients' adherence to medication, which is a patient safety practice with risk for harm if medications are not taken as prescribed. Patient education, self-management programs, and online access to their physician's clinical notes all improved medication adherence (appendix exhibit A7, articles 1–4).²⁰

Nine reviews, ranging in quality from medium to low, discussed patients' and caregivers' roles in safety-event reporting, which is typically related to reporting adverse medication events (appendix exhibit A7, articles 5–13).²⁰ These roles included pharmacovigilance, meaning opportunities for patients to disclose medication adverse events directly to state-based databases, health care systems, or pharmaceutical companies. All but one of the reviews noted that patients and families reported events that were distinct, more frequent, or novel, compared to events identified by health care providers. For example, one medium-quality review showed that patients who received treatment for rectal cancer more frequently reported chemotherapy toxicity and bowel and sexual dysfunction than health care providers (appendix exhibit A7, article 6).²⁰ Patients reported safety issues as well as events that involved suboptimal service quality or communication problems (appendix exhibit A7, article 7).²⁰

Five reviews addressed patient engagement in reducing medication administration errors. Three reviews ranging in quality from medium to low described a positive impact of patient or family education that focused on medication reconciliation: improved medication administration accuracy (appendix exhibit A7, articles 15, 16, and 18).²⁰ One medium-quality review found that the incidence of patient medication self-administration error was 19–59 percent (appendix exhibit A7, article 14).²⁰ One low-quality review found that patients and families could reduce errors in chemotherapy administration (appendix exhibit A7, article 17).²⁰

ADMINISTRATIVE ERRORS

Four reviews explored patient engagement to improve documentation and scheduling accuracy. One high- and one medium-quality systematic review reported that online patient portals, in which patients could review their charts, could allow patients to correct their medication lists or electronic medical records (EMRs) (appendix exhibit A8, articles 1 and 2).²⁰ One low-quality systematic review described how an advisory council led a communitywide initiative that resulted in patients' updating and correcting their medication lists (appendix exhibit A8, article 4).²⁰

One low-quality review (appendix exhibit A8, article 3)²⁰ assessed the impact of patient-accessed web-based medical appointment systems. It found that giving patients web-based access improved appointment attendance and reduced scheduling errors.

DIAGNOSTIC ERRORS

One high-quality review assessed the role of patient engagement in diagnostic error, reporting that patients seeking a second opinion found a major change in the diagnosis, treatment, or prognosis in 10–62 percent of cases. However, this finding was based on low-quality primary data (appendix exhibit A9, article 1).²⁰

MALPRACTICE LAWSUITS

One high-quality review (appendix exhibit A10, article 1)²⁰ assessed shared decision-making tools as a patient engagement strategy to prevent malpractice litigation. The review found insufficient evidence of any impact.

HOSPITAL READMISSIONS

Six medium-quality reviews assessed the impact of patient engagement on preventing hospital readmissions for conditions such as heart failure, pneumonia, and chronic obstructive pulmonary disease. Two reviews reported that patient or family education programs reduced readmissions (appendix exhibit A11, articles 2 and 6),²⁰ while one reported that a structured discharge process did not have an impact on preventing readmissions (appendix exhibit A11, article 1).²⁰ Two reviews assessed self-management strategies: One reported positive results (appendix exhibit A11, article 4),²⁰ and the other reported null results (appendix exhibit A11, article 3).²⁰ One review found null results of community health worker support (appendix exhibit A11, article 5).²⁰

HEALTH CARE–ASSOCIATED INFECTIONS

Health care workers' failure to adhere to hand hygiene increases the risk of health care–associated infections. Four reviews, with quality ranging from medium to low (appendix exhibit A12, articles 1–4),²⁰ reported on the feasibility of patient and family engagement in hand hygiene initiatives. One study found that an educational program to encourage patients to ask health care workers to wash their hands resulted in increased compliance with hand hygiene standards by 52 percent and a 32 percent decrease in infections (appendix exhibit A12, article 3).²⁰

PRESSURE ULCERS

One low-quality review detailed the effect of patients' and caregivers' involvement in preventing pressure ulcers. The authors reported that self-management technologies had low-to-moderate effectiveness in addressing some risk factors for pressure ulcer development (appendix exhibit A13, article 1).²⁰

Discussion

This overview of reviews demonstrates that a range of patient engagement interventions led to improved safety. While prior literature surveys have concluded that the evidence base is scant, there has been an abundance of research on patient engagement since Hall and coauthors' 2010 systematic review.¹³ This evidence base has been scattered across the literature for specific diseases and disciplines, which makes it challenging to identify common themes and interpret best practices.

The reviews varied in study quality and risk of bias. Our highest-quality, most robust finding was the consistently positive impact of patient self-management and self-monitoring of warfarin for anticoagulation to reduce mortality and thromboembolic events. With the majority of chronic disease management occurring between office visits, in the home and community, self-monitoring and self-management strategies can help patients and families maintain safety between visits with their health care providers (see appendix exhibit A14).²⁰

Despite high-quality evidence of its effectiveness, patients' self-monitoring of anticoagulation medication is rare in clinical practice. This is a major implementation gap. Contributing factors may include clinicians' discomfort with delegating responsibility to patients, challenges in obtaining insurance coverage for home monitors, and the growing shift to novel oral anticoagulants.²² Similar barriers may prevent the implementation of other patient engagement strategies identified in our review, such as the use of self-management tools to prevent hypoglycemia, self-management support after discharge, and pressure ulcer self-monitoring.

Research Gaps

We identified multiple research gaps in this overview. The evidence for patient self-management to prevent anticoagulation medication adverse events and hypoglycemia suggests that other high-risk medications could be safer with patient self-management support. Anti-arrhythmics, antihypertensives, and opioids require frequent monitoring or office visits and are commonly implicated in outpatient adverse events.²³ Their safety could be improved with patient engagement in between-visit symptom monitoring and dosage self-adjustment. In light of the growing opioid epidemic, further research on self-management and monitoring for opioid adverse effects should be prioritized. A recent program exemplified this approach: It used education and team-based support to engage patients in self-tapering of opioids, which showed reduction in opioid burden with no change in mean pain intensity.²⁴

We identified only one review that addressed system-level patient engagement: It reported that community advisory councils promoted patients and families' corrections of discrepancies or inaccuracies in their own medication lists on a population level (appendix exhibit A8, article 4).²⁰ Patient safety research should examine the effects of system-level participation, such as participation in root cause analysis, and the emerging field of experience-based codesign to redesign care processes. One example of system-level patient engagement research is a pre-post analysis that found a dramatic reduction in medication errors after patient and family advisers were embedded within quality and safety committees across an institution.²⁵

Other than studies of readmission prevention, we found little research on patient safety through engagement with other members of the care team, including family caregivers, home health aides, pharmacists, and nurses. No studies examined the integration of patient safety across the medical neighborhood—partnerships across the medical and social drivers of health that connect clinicians, patients, hospitals, home health, and community organizations.²⁶ Integrated models of care align care domains that are usually fragmented, to promote patient and family engagement.

Only one of the systematic reviews addressed patient engagement in diagnostic errors, defined narrowly as seeking second opinions. Patients can reduce diagnostic errors in a variety of ways that merit further study, such as patient education regarding testing follow-up, patients' reporting of diagnostic errors, or participating in advisory councils that review such errors.²⁷

Policy Implications

Unlike the situation highlighted by the findings of the 2010 review,¹³ health care is now at a stage where patient engagement safety initiatives are being implemented and tested in a diverse range of care settings. No study has shown evidence of harm from patient engagement, and many have shown improvements in safety outcomes. Up to now, policy mandates for patient engagement within safety have typically been general and diffuse. We recommend that policies supporting patient engagement specifically describe what the engagement modality entails, including a robust safety evaluation plan. Policies that encourage an implementation science approach will be paramount if the science is to move to the next stage.

Supportive policies for health information technology may enhance patient engagement within safety. Our review highlights the importance of EMR-based patient portals, which allow patients to access laboratory results and medication lists and communicate with providers. Programs such as OpenNotes, which patients can use to review all of their clinical documentation, were highlighted in our overview as a way to identify both administrative and diagnostic errors. However, only a small percentage of patients with higher educational attainment and literacy engage with portals,²⁸ and current EMRs lack interoperability. For EMRs and patient portals to achieve their full potential as patient engagement tools for safety, policy shifts must encourage interoperable systems that accommodate patients with

limited health literacy and English proficiency and facilitate access for caregivers as well.
29,30

Patient safety event reporting has a critical mass of evidence to support its efficacy and now needs broader implementation. Our review demonstrated that patients and families consistently identify and report adverse events that are unique and often more expansive than those identified by health care workers. Patient reports also capture outcomes that are more relevant to function and quality of life. However, few health care systems provide easy, anonymous systems for patients and families to submit reports of adverse events outside of a formal grievance process, especially in the office practice, home, and community. Some European countries already have national reporting systems in place that could serve as templates (appendix exhibit A7).²⁰ EMR-based patient portals could also be a platform for the direct reporting of adverse events.^{31,32}

Investments in digital self-management tools and apps are growing. However, our review found little evidence supporting tech-based self-management devices. We identified only one high-quality review that addressed the role of digital apps (appendix exhibit A6, article 2),²⁰ and it reported mixed results for preventing hypoglycemia in diabetes, based on low-quality primary data. Digital self-management tools that support home monitoring of specific high-risk conditions deserve further exploration—with robust safety endpoints, rather than just feasibility or usability, as primary outcomes.

We excluded reviews that assessed patient engagement tools to reduce unnecessary medical treatments, such as shared decision making to reduce antibiotic use for upper respiratory infections.³³ We also excluded reviews that assessed patient engagement in chronic disease management and reported care quality outcomes that had risk for patient harm, such as seizure frequency among patients with known epilepsy.³⁴ While this review focused on high-priority safety outcomes, health care systems that engage with patients to limit overtreatment and deliver high-quality chronic disease management may also be safer.

The strengths of this overview include an expansive search strategy to uncover and synthesize a broad range of the literature on patient engagement, spanning pharmacology, primary and subspecialty care, health information technology, and policy journals. Our review is the first to comprehensively organize patient engagement evidence by principles of patient safety, rather than by subspecialty areas or specific disease states.

Conclusion

Patients and families experience adverse events that health professionals may miss, and they self-manage care between office visits and care transitions with limited support. The past ten years have yielded a major expansion in research and policy to explore the role of patient and family engagement in health care safety outcomes. Future work should foster new modalities for patients and families to self-manage care and communicate easily with care teams, the innovative use of EMRs, and patients' participation in system-level safety improvements. The patient has been “in” patient safety all along. The next step is for health

care teams to partner with patients and caregivers to integrate effective patient engagement into clinical practice and health care systems. ■

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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EXHIBIT 1

Safety domains addressed by systematic review for which research gaps remain

Safety target or condition	Patient engagement intervention key findings	Readiness for broad-scale adoption	Recommendations for closing research gaps
Anticoagulation management: bleeding, thromboembolism, anticoagulant-related mortality	INR self-monitoring and/or anticoagulant self-titration reduces thromboembolism and mortality, mixed effect on bleeding Self-efficacy intervention reduces thromboembolism and bleeding	High readiness for adoption, but implementation lags behind; limitations include patient and provider readiness, distribution costs, and clinic infrastructure	Delineate barriers to implementation Explore whether anticoagulation evidence is applicable to the self-management of other high-risk medications such as insulin and opioids
Hypoglycemia in diabetes	Self-management education reduces hypoglycemia in people with type 1 diabetes Digital apps/tools: mixed evidence for types 1 and 2 diabetes Patient activation interventions: null impact for type 2 diabetes	Limited readiness for adoption given the mixed evidence base; patient self-management education lacks a reimbursement mechanism	Meta-analyses are needed to explore the safety of digital apps/tools
Medication safety: medication adherence	Positive impact on adherence: medication self-monitoring and self-management; online access to notes; pharmacist education; simplified dosing regimens	High readiness for adoption; safety benefits of patient engagement to support medication adherence are not currently disseminated	Explore caregiver role in supporting medication adherence
Medication safety: pharmacovigilance, other adverse events	Patients' reports of adverse events and postmarketing medication adverse events are distinct from and more expansive than provider reports	Already implemented in many European countries; US limitations include interoperability between EMRs, the FDA, and pharmaceutical companies	Investigate prospectively whether patients' reports reduce or prevent adverse events.
Medication safety: medication administration	Effective reduction of administration errors: patient education, patient monitoring	Adequate evidence base; EMR interoperability across prescribers, pharmacy, and home care limits adoption	Home and community-based studies needed Trials should be integrated between community pharmacies and prescribers
Hospital readmissions	Postdischarge symptom self-monitoring and self-management: mixed evidence Patient and family discharge education: mixed evidence Community health worker support: null impact	Moderate readiness for adoption; efficacy is mixed, but postdischarge monitoring may be important for high-risk patients	Explore the role of family education and support Study the roles of health coaches, navigators, and health care workers explicitly for readmission and safety outcomes

SOURCE Authors' analysis of major findings from fifty-two articles that met the study's inclusion criteria. **NOTES** A version of the table with full results is available as online appendix exhibit A4 (see note 20 in text). INR is international normalized ratio, which is the lab test necessary to monitor warfarin for anticoagulation. EMR is electronic medical record. FDA is Food and Drug Administration.