

# Engaging Family Caregivers With Structured Communication for Safe Care Transitions

*Rapid Review*



## Structured Abstract

**Objectives.** To summarize recent relevant literature on patient safety practices (PSPs) focused on engaging family caregivers with structured communication during care transitions and assess the effectiveness of these PSPs to improve safety during care transitions. This review provides information for clinicians, health system leaders, and policymakers to better inform approaches to engaging family caregivers with structured communication to improve safety during care transitions.

**Methods.** We followed rapid review processes provided by the Agency for Healthcare Research and Quality Evidence-based Practice Center Program. We searched PubMed, Embase, and the Cochrane Library for eligible studies published in 2010 through June 30, 2023, supplemented by targeted gray literature searches and review of reference lists in relevant systematic reviews. We used prespecified inclusion and exclusion criteria to assess relevant studies conducted in the United States that analyzed the effect of structured communication on care transitions with family caregivers. Prespecified clinical and patient-related outcomes included healthcare utilization, symptom exacerbation, quality of life, satisfaction, and unintended harms, among others.

**Findings.** We identified 323 unique citations for possible inclusion; we assessed 86 full-text articles for inclusion. We included nine studies on effectiveness (2 randomized controlled trials, 6 pre-post studies, and 1 single-arm study) which assessed PSPs focused on discharge to home, transfers from intensive care units, and transitions from residential care. In residential treatment facility discharges, we found PSPs improved caregiver satisfaction (low strength of evidence [SOE]). We found insufficient evidence of other PSPs on any other included outcomes. Five studies detailed implementation facilitators, and two studies noted specific barriers to PSP implementation. While no studies specifically reported the resources required to



implement PSPs, based on study descriptions, we identified four prominent resource considerations: (1) allocated time for pre-implementation intervention development and staff training; (2) designated time to deliver PSPs to family caregivers; (3) technology-based resources; (4) staff-expertise/addition training for designated roles. None of the studies reported rates of unintended harms.

**Conclusions.** Clear communication with patients and caregivers during care transitions is important, but there is little evidence on the effectiveness of these PSPs. Included studies showed improvement in caregiver satisfaction, but more high-quality research is needed to assess the effectiveness of PSPs and unintended harms.

# Contents

<b>1. Background and Purpose</b> .....	<b>5</b>
1.1 Overview of Engaging Family Caregivers With Structured Communication for Safe Care Transitions .....	5
1.2 Purpose of the Rapid Review .....	7
1.3 Review Questions .....	7
<b>2. Methods</b> .....	<b>8</b>
2.1 Eligibility Criteria for Studies of Effectiveness .....	8
2.2 Literature Searches for Studies of Effectiveness .....	10
2.3 Data Extraction (Selecting and Coding) .....	10
2.4 Risk of Bias (Quality) Assessment .....	10
2.5 Strategy for Data Synthesis .....	11
<b>3. Evidence Summary</b> .....	<b>12</b>
3.1 Benefits and Harms .....	12
3.2 Future Research Needs .....	12
<b>4. Evidence Base</b> .....	<b>13</b>
4.1 Number of Studies .....	13
4.2 Findings for Review Questions .....	14
<b>5. Discussion</b> .....	<b>39</b>
5.1 Summary and Interpretation of Findings .....	39
5.2 Limitations .....	39
5.3 Implications for Clinical Practice and Future Research .....	40
<b>6. References</b> .....	<b>42</b>

## Tables

Table 1. Inclusion and exclusion criteria .....	9
Table 2. Characteristics of included studies .....	19
Table 3. Details of studies focused on hospital discharge care transitions .....	23
Table 4. Details of studies focused on transfers from intensive care units .....	28
Table 5. Details of studies focused on other care transitions .....	31
Table 6. Strength of evidence ratings .....	33
Table 7. Patient safety practice implementation facilitators and barriers .....	36

## Figures

Figure 1. Literature flow diagram .....	13
Figure 2. Risk of bias assessments for randomized controlled trials .....	20
Figure 3. Risk of bias assessments for nonrandomized studies .....	20

## **Appendixes**

Appendix A. Literature Search Strategies

Appendix B. Evidence Tables

Appendix C. Risk of Bias Assessment

Appendix D. List of Excluded Studies with Reasons Upon Full-Text Review



# 1. Background and Purpose

The Agency for Healthcare Research and Quality (AHRQ) Making Healthcare Safer (MHS) reports consolidate information for healthcare providers, health system administrators, researchers, and government agencies about practices that can improve patient safety across the healthcare system—from hospitals to primary care practices, long-term care facilities, and other healthcare settings. In spring 2023, AHRQ launched its fourth iteration of the MHS Report (MHS IV), which is available at <https://www.ahrq.gov/research/findings/making-healthcare-safer/mhs4/index.html>. Engaging Family Caregivers with Structured Communication for Safe Care Transitions was identified as high priority for inclusion in the MHS IV reports using a modified Delphi technique by a Technical Expert Panel (TEP) that met in December 2022. The TEP included 15 experts in patient safety with representatives of governmental agencies, healthcare stakeholders, clinical specialists, experts in patient safety issues, and a patient/consumer perspective. See the Making Healthcare Safer IV Prioritization Report<sup>1</sup> (available at: <https://effectivehealthcare.ahrq.gov/products/prioritization-patient-safety-practices>) for additional details.

Care transitions, particularly those from the inpatient or emergency settings to outpatient settings, represent a critical point in patient care. Potential disruptions in the continuity and coordination of care during transitions may lead to adverse outcomes such as new hospitalizations or readmissions, emergency department (ED) visits, and exacerbations of health conditions.<sup>2,3</sup> The presence of family caregivers throughout the transition process can potentially help prevent such adverse outcomes. Furthermore, if healthcare professionals use structured communication approaches, patients and caregivers may better understand what to expect, what the next steps in care are, and what resources are available during inpatient and emergency care as well as the outpatient setting (e.g., home, long-term care facilities).

## 1.1 Overview of Engaging Family Caregivers With Structured Communication for Safe Care Transitions

Caregivers are individuals who assist others with social or health needs, supporting others in a number of ways including bathing and eating, providing community and health-related transportation, medication management, ongoing care coordination and communication, and/or managing a chronic condition.<sup>4,5</sup> Family caregivers are informal or unpaid adult caregivers providing support to a family member or friend<sup>6</sup> and includes relatives, friends, partners, or others who have a close personal relationship with the individual they are supporting.<sup>5,7</sup> As of 2020, approximately 53

million American adults (21.3%) reported being a caregiver with 14.1 million (5.7%) and 41.8 million (16.8%) caring for an individual aged less than 18 years or more than 49 years, respectively.<sup>6</sup>

Care transitions refers to when patients move between healthcare practitioners or settings as their care needs change.<sup>8</sup> This rapid review focuses on care transitions involving family caregivers either within or between healthcare settings (e.g., intensive care unit to hospital; hospital to skilled nursing facility), or from an inpatient or emergency setting to an outpatient setting where family caregivers are primarily responsible for continuing care for the patient.

Clear communication between healthcare professionals and between caregivers and patients is an important aspect of delivering quality healthcare at points of care transitions<sup>9</sup> and is a key component of frameworks to improve patient safety during transitional care.<sup>10-12</sup> Patients and caregivers desire and may benefit from better communication at transitions of care.<sup>11,13-15</sup>

Structured communication is an approach to improve verbal interactions via use of standardized procedures, tools, or templates, with the goal of facilitating clear and complete sharing of relevant information and better understanding by all parties. Healthcare professionals use structured communication techniques to deliver information between each other and to caregivers and patients. Structured communication differs from unidirectional information sharing with family caregivers, such as discharge instructions and patient education handouts. Structured communication allows for interactions with family caregivers allowing them to express their concerns, while simultaneously allowing clinical providers to assess their understanding of the treatment plan and correct misunderstandings in real time. Further, the structured communication is not necessarily a one-time event; instead the communication protocols can extend beyond the initial care transition through ongoing communication and interaction.

Examples of structured communication tools and approaches include, among others, the Teach-Back Method,<sup>16,17</sup> checklists,<sup>18</sup> the I-PASS tool,<sup>19,20</sup> and computer-assisted programs<sup>21,22</sup> and modules embedded within electronic health records. For discharge to the home, the communication to caregivers can include content such as medication administration, wound care, and the timing of followup appointments. Structured communication approaches help healthcare professionals establish communication processes and instruments to guide a conversation to ensure other individuals (e.g., other healthcare professionals, caregivers, patients) comprehend the next steps in care and know how and when to access additional support from the healthcare system. These approaches may improve direct health and utilization outcomes for patients, but may also impact the experience of post-transitional care for family caregivers who often experience additional stress and burden due to their caregiving responsibilities.

This topic, which was not covered in previous Making Healthcare Safer (MHS) reports, differs in a few ways from the concurrent MHS IV rapid response on Patient

and Family Engagement.<sup>23</sup> This rapid review is specific to structured communication related to care transitions. Consequently, it can involve an intervention that only provides information to family caregivers (unlike the rapid response on Patient and Family Engagement, which excluded information-only interventions). Secondly, it only addresses care transitions in multiple healthcare settings, whereas the scope of the rapid response on Patient and Family Engagement included interventions within a single setting. Third, unlike the rapid response, which only included interventions directed at patients and/or family members, this topic includes interventions specifically targeted at family caregivers (i.e., informal caregivers), who may or not be actual family members. In the prioritization process, the Making Healthcare Safer IV TEP noted that it may be beneficial to refine how structured communication is defined for these patient safety practices (PSPs).

## **1.2 Purpose of the Rapid Review**

The overall purpose of this review is to summarize recent relevant literature on PSPs focused on engaging family caregivers with structured communication during care transitions and assess the effectiveness of these PSPs to improve safety during care transitions. We also sought to identify unintended harms of these PSPs as described in relevant studies.

## **1.3 Review Questions**

1. What is the frequency and severity of harms associated with care transitions?
2. What patient safety measures or indicators have been used to examine these harms?
3. What PSPs (including Engaging Family Caregivers with Structured Communication for Safe Care Transitions) have been used to prevent or mitigate the harm and in what settings have they been used?
4. What is the rationale for these PSPs?
5. What are the effectiveness and unintended effects of these PSPs?
6. What are common barriers and facilitators to implementing these PSPs?
7. What resources (e.g., cost, staff, time) are required for implementation?
8. What toolkits are available to support implementation of these PSPs?



## 2. Methods

We followed processes proposed by the Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center (EPC) Program.<sup>24</sup> The final protocol for this rapid review is available on the AHRQ website at: <https://effectivehealthcare.ahrq.gov/products/engaging-caregivers-mhs4/protocol>. We registered the protocol for this rapid review in PROSPERO (registration number CRD42023457526).

For this rapid review, strategic adjustments were made to streamline traditional systematic review processes and deliver a rapid evidence product. Adjustments included being as specific as possible about the questions, limiting the number of databases searched, modifying search strategies to focus on finding the most valuable studies (i.e., being flexible on sensitivity to increase the specificity of the search) published recently in English, and restricting the inclusion criteria to studies performed in the United States, and having each study assessed by a single reviewer. We used the artificial intelligence (AI) feature of DistillerSR (AI Classifier Manager), such that we re-reviewed the top 30 percent of excluded citations that the AI Classifier Manager noted as potentially includable.

For this topic, we asked our content experts to answer Review Questions 1 and 2 by citing selected references that best answer the questions without conducting a systematic search for all evidence on the targeted harms and related patient safety measures or indicators.

For Review Question 2, we focused on identifying relevant measures included in the Centers for Medicare & Medicaid Services (CMS) patient safety measures, AHRQ's Patient Safety Indicators, or the National Committee for Quality Assurance (NCQA) patient safety related measures. We asked our content experts to answer Review Questions 3 and 4 by citing selected references, including PSPs used and explanations of the rationale presented in the studies we found for Review Question 5. For Review Questions 6 and 7, we focused on the barriers, facilitators, and required resources reported in the studies we found for Review Question 5. For Review Question 8, we searched for publicly available patient safety toolkits developed by AHRQ and other organizations that could help to support implementation of the PSPs. To accomplish this, we reviewed AHRQ's Patient Safety Network (PSNet) and AHRQ's listing of patient safety related toolkits,<sup>25,26</sup> and we also included toolkits mentioned in the studies we found for Review Question 5. We did not assess and do not endorse any of the identified toolkits.

### 2.1 Eligibility Criteria for Studies of Effectiveness

We searched for original studies and systematic reviews on Review Question 5 according to the inclusion and exclusion criteria presented in Table 1. Because there is



not a clear definition of what constitutes “structured communication,” we erred on the side of inclusion of interventions for improving communication with family caregivers that use standardized approaches or specific instruments/tools to structure conversations around care transitions.

**Table 1. Inclusion and exclusion criteria**

Study Parameter	Inclusion Criteria	Exclusion Criteria
Population	Patients and family caregivers <sup>a</sup> experiencing care transitions within or between inpatient and emergency settings or from a care setting to an outpatient setting. If the inpatient literature includes 10 or more studies, we will focus only on transitions to outpatient settings.	<ul style="list-style-type: none"> <li>Care transitions that do not include a family caregiver</li> </ul>
Intervention	Structured communication (i.e., use of standardized approaches or specific instruments/tools to facilitate conversations) with family caregivers for care transitions	<ul style="list-style-type: none"> <li>Nonstructured communication</li> <li>Structured communication only with patients</li> <li>Communication between healthcare professionals</li> </ul>
Comparator	Any comparator, including pre-intervention measurements	No comparator
Outcome	<ul style="list-style-type: none"> <li>Post care transition:               <ul style="list-style-type: none"> <li>ED utilization</li> <li>Hospital admission/readmission</li> <li>Symptom/condition exacerbation</li> <li>Mortality</li> <li>Continuity of care measures</li> <li>Medication errors in transitioned setting</li> </ul> </li> <li>Caregiver burden/stress</li> <li>Patient/caregiver satisfaction</li> <li>Quality of care</li> <li>Unintended consequences and harms of structured communication with family caregivers for care transitions</li> </ul>	Other outcomes (e.g., patient/caregiver understanding, medication adherence, provider satisfaction)
Timing	Original studies and systematic reviews published in 2010 through June 30, 2023	Before 2010
Setting	Any care setting or transition to an outpatient setting	No exclusions
Followup	Any followup	No exclusions
Study Design	RCTs, nonrandomized trials, and observational studies with a comparison group	<ul style="list-style-type: none"> <li>Unspecified study designs or comparison group not described</li> <li>Comparator group is not appropriate (would not have equivalent exposure to the intervention)</li> <li>Qualitative studies</li> </ul>

**Abbreviations:** ED = emergency department; RCT = randomized controlled trial.

<sup>a</sup> Family caregivers includes family members and any nonfamilial informal or unpaid caregivers who provide caregiving support to a patient (e.g., friend, neighbor).

## 2.2 Literature Searches for Studies of Effectiveness

A research librarian searched PubMed, Embase, and the Cochrane Library for relevant citations published in 2010 through June 30, 2023. We limited studies to those published in 2010 or later in order to complete this rapid review in a timely manner, and also capture all recently published studies that are likely to be relevant to current practice. A 2020 review<sup>27</sup> of a similar topic included 40 studies, and only 2 were published before 2010. We supplemented the database searches with a narrowly focused search for unpublished reports that are publicly available from governmental agencies (e.g., AHRQ) and nonprofit research organizations (e.g., Patient-Centered Outcomes Research Institute) having a strong interest in the topic. **Appendix A** contains the details of the search strategy.

## 2.3 Data Extraction (Selecting and Coding)

To efficiently identify studies that meet the eligibility criteria, the title and abstract of each citation was reviewed by a single team member. We used the DistillerSR AI Classifier Manager to identify potentially highly relevant studies excluded during the initial screening. That is, after a single team member reviewed each citation, we re-reviewed the top 30 percent of excluded abstracts noted by the AI Classifier Manager as potentially relevant. The full text of each remaining potentially eligible article were reviewed by a single team member to confirm eligibility and extract data. A second team member reviewed a randomly selected 10 percent sample of the excluded full text articles to verify that important studies were not excluded and confirm the accuracy of extracted data.

We organized information according to the review questions, and noted the author, year, study design, frequency and severity of the harms, measures of harm, characteristics of the PSP, rationale for the PSP, outcomes, implementation barriers and facilitators, required resources, and descriptions of toolkits. To streamline data extraction, we focused on extracting information about characteristics, outcomes, and barriers/facilitators most pertinent to these PSPs.

## 2.4 Risk of Bias (Quality) Assessment

A single reviewer assessed the risk of bias of included studies. For studies addressing Question 5 about the effectiveness of these PSPs, we used the Cochrane Collaboration's tool for assessing the risk of bias of randomized controlled trials (RCTs) or the ROBINS-I tool for assessing the Risk Of Bias In Non-randomized Studies of Interventions.<sup>28,29</sup> When assessing RCTs, we used the 7 items in the Cochrane Collaboration's tool that cover the domains of selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias.<sup>30</sup> When assessing

nonrandomized studies, we used specific items in the ROBINS-I tool that assess bias due to confounding, bias in selection of participants into the study, bias in classification of interventions, bias due to deviations from intended interventions, bias due to missing data, bias in measurement of outcomes, and bias in selection of the reported results.<sup>29</sup> The risk of bias assessments focused on the main outcome of interest in each study.

## **2.5 Strategy for Data Synthesis**

We compiled selected data into evidence tables and synthesized studies narratively. We did not conduct a meta-analysis. For Review Question 5 about the effectiveness of these PSPs, we recorded information about the context of each study and whether the effectiveness of the PSP differed across patient subgroups. We rated the strength of evidence for these PSPs using the methods outlined in the AHRQ Effective Health Care Program (EHC) Methods Guide for Effectiveness and Comparative Effectiveness Reviews,<sup>31</sup> and focused on relevant outcomes listed in Table 1.



## 3. Evidence Summary

### 3.1 Benefits and Harms

- Structured communication with family caregivers improved family caregiver satisfaction in residential treatment discharge (Strength of evidence [SOE]: Low)
- There is insufficient evidence to assess the effect of structured communication with family caregivers on:
  - 30-day hospital readmissions
  - emergency department (ED) visits,
  - caregiver stress in hospital settings,
  - caregiver anxiety and depression
  - family/patient satisfaction for intensive care unit (ICU) transfers, and
  - symptom exacerbation in adolescents discharged from residential treatment facilities
- None of the studies reported rates of unintended harms

### 3.2 Future Research Needs

Future research needs include:

- methodologically rigorous studies of structured communication with family caregivers
- assessment of impacts on medication errors following care transitions
- resource requirements for implementation of structured communication with family caregivers
- assessment of potential harms or unintended consequences of interventions
- tailored interventions that include diverse patient populations and consider socioeconomic factors, spoken language, and health literacy

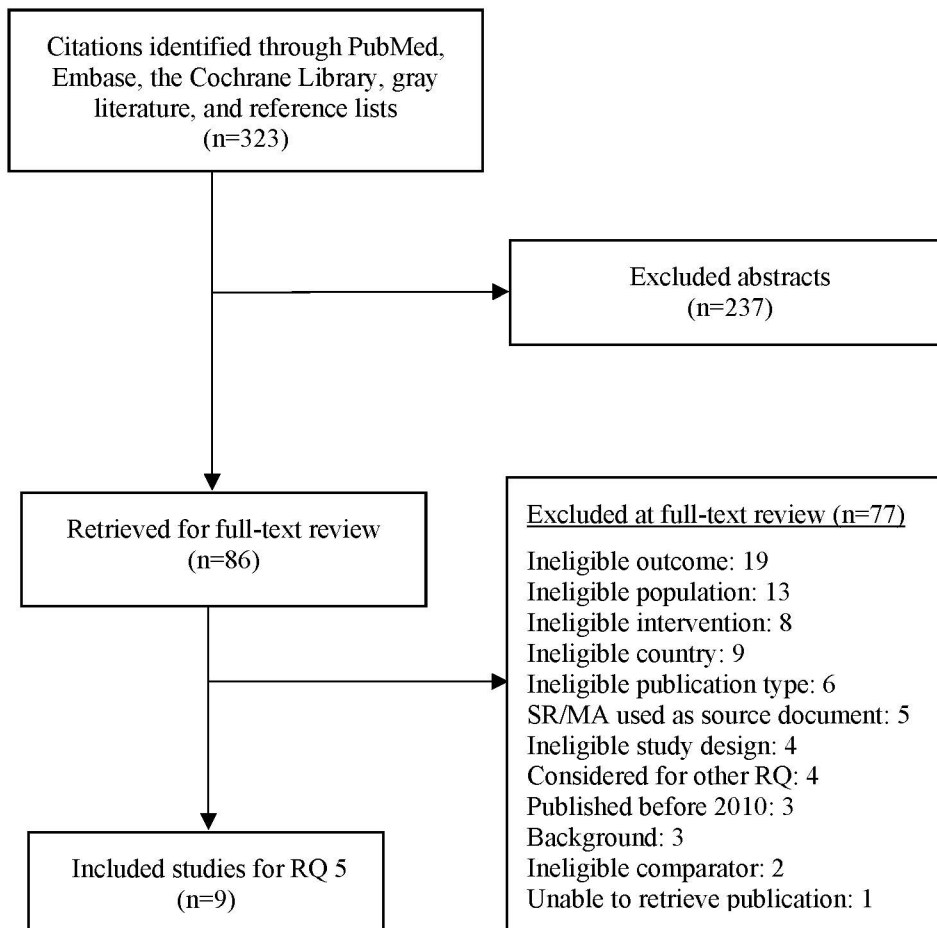


## 4. Evidence Base

### 4.1 Number of Studies

We identified 323 unique titles and abstracts, and we assessed 86 full text articles for inclusion. Nine studies met inclusion criteria for Research Question 5 and are included in the evidence base. **Figure 1** details the literature flow process. **Appendix B** and **Appendix C** provide evidence tables with additional study details and risk of bias assessments for included studies. **Appendix D** contains a list of studies excluded after full text review and reasons for exclusion.

Figure 1. Literature flow diagram



Abbreviations: RQ = Research Question; MA = meta-analysis; SR = systematic review

## 4.2 Findings for Review Questions

### 4.2.1 Question 1. What Are the Frequency and Severity of Harms Associated With Care Transitions?

There are numerous harms associated with care transitions. For this review, we focused on PSPs targeting harms related to communication during care transitions.

Consequences of miscommunication during care transitions include patient/caregiver mistrust; caregiver anxiety, depression, and stress/burden; family conflict; increased healthcare utilization (e.g., hospital readmissions, ED visits), medication errors, exacerbation of symptoms, and delayed patient recovery.<sup>15</sup> Although these harms are widely acknowledged, an accurate assessment of their frequency and severity is sparse. One 2003 study<sup>32</sup> assessing hospital to home care transitions in 400 patients found that 19 percent of patients experienced adverse events (AEs) within a 2-week followup period, 30 percent of which were preventable.

### 4.2.2 Question 2. What Patient Safety Measures or Indicators Have Been Used To Examine These Harms?

The Centers for Medicare & Medicaid Services (CMS) patient safety measures and the Agency for Healthcare Research and Quality (AHRQ) Patient Safety Measures measures or indicators do not specifically address care transitions or patient/caregiver communication. We also did not find any National Committee for Quality Assurance (NCQA) measures focused specifically on structured communication with family caregivers in care transitions, but the NCQA Patient Centered Medical Home (PCMH) program notes that a core concept of the PCMH model is to communicate effectively with patients and families/caregivers, ostensibly to enhance patient access to medical providers to receive clinical advice or medical records whenever needed.<sup>33</sup>

Many of the outcomes in our inclusion criteria address harms associated with care transitions. We intentionally searched for studies that analyzed intervention effects on hospital readmissions, ED visits, symptom exacerbation, and medication errors. The studies we included in this review reported outcomes on ED visits, hospital readmissions, and symptom exacerbation, but not on medication errors following discharge. Studies also reported patient and caregiver satisfaction, anxiety, burden, and depression.

### **4.2.3 Question 3. What PSPs (Including Engaging Family Caregivers With Structured Communication for Safe Care Transitions) Have Been Used To Prevent or Mitigate the Harm and in What Settings Have They Been Used?**

Six<sup>20,34-38</sup> of the nine studies included in our analysis used various approaches to structured communication with family caregivers and reported patient safety-related outcomes in different care settings.

Four studies<sup>20,35,36,38</sup> reported on ED visits and hospital readmissions; all were hospital-based and focused on hospital discharge to home care. One study<sup>38</sup> resulted in the development of SAFER Care and provided worksheets in Spanish and English to caregivers. The worksheet consisted of six prompted questions caregivers should ask medical providers before hospital discharge. A family liaison also met with caregivers at least once during admission to review the SAFER Care framework and provide additional worksheets if needed. Another study in hospitalized patients with heart failure<sup>36</sup> used teach-back education based on questions from the Institute for Healthcare Improvement's (IHI) recommendations for ideal transitions<sup>39</sup> and tailored them to be patient specific. A third study<sup>35</sup> used a modified 25-item checklist based on AHRQ's Re-Engineered Discharge Toolkit<sup>40</sup> and CMS discharge planning requirements.<sup>41</sup> A fourth study<sup>20</sup> incorporated the I-PASS framework in a multicomponent intervention focusing on verbal and written conversations with families following discharge and communication between inpatient and outpatient healthcare providers of hospitalized children with complex medical conditions. The intervention consisted of a followup call from a nurse using a structured template with families 24 to 48 hours after hospital discharge, a structured discharge summary, and a written summary that was saved in an electronic health record from inpatient providers to all outpatient providers. This study also assessed post-discharge incidents which included medication errors, communication errors, and preventable and nonpreventable adverse events.

Two studies that assessed caregiver stress, anxiety, or depression<sup>34,37</sup> developed multicomponent PSPs using health/family navigators. One study focused on hospital discharge<sup>34</sup> and the other study focused on ICU transfers.<sup>37</sup> Health/family navigators' specific expertise varied in the two studies, but in general, navigators were trained healthcare workers with a distinct role to assess individualized health and social needs, and coordinate relevant support services for patients and family caregivers during and after their hospitalizations.

Three studies<sup>42-44</sup> used different PSPs for structured communication with family caregivers but did not specifically report on patient safety-related outcomes. One study<sup>42</sup> was set in a residential treatment center for adolescents with substance abuse problems and used a multicomponent PSP. Another study<sup>43</sup> targeted ICU transfers and used family meetings to communicate with family caregivers. The

third study<sup>44</sup> targeted ICU transfers and used an ICU-diary to assist in communication with caregivers and patients.

#### 4.2.4 Question 4. What Is the Rationale for These PSPs?

Family caregivers have articulated a need for support in the post-discharge period to help with problem-solving, decision making, and accessing followup care and community-based programs.<sup>45</sup> Family caregivers often provide critical support services for patients experiencing transitions of care, such as help with medication management, use of medical devices, managing special diets, assistance with care tasks (e.g., wound care, giving injections), and assistance with basic daily activities during recovery after discharge.<sup>46-48</sup> Family caregivers also play a key role in coordinating followup ambulatory care services and managing healthcare related forms and finances. An estimated 78 percent of family caregivers help significant others manage medications, 53 percent help with care coordination, and 46 percent assist in general medical and nursing tasks.<sup>49,50</sup>

Despite their critical role, family caregivers are not often systematically engaged during care transitions, and discharge plans are often developed without engaging family caregivers. Family caregivers often report poor communication and involvement with healthcare teams around discharge planning, being unprepared for taking care of their loved ones following hospital discharge,<sup>51-53</sup> and receiving inadequate information and training to perform caregiving roles.<sup>49,54</sup> Family caregivers also report inadequate education for safely managing patient medications and receiving limited training about home care tasks needed to ensure positive patient outcomes after discharge.<sup>55</sup>

All but seven U.S. states adopted the CARE (Caregiver, Advise, Record, Enable) Act,<sup>48</sup> but a recent survey showed that family caregiver education is taking place in only about 32 percent of all hospital stays.<sup>56</sup> A qualitative study of 138 patients and 110 caregivers from six U.S. healthcare networks reported caregivers feel they are not adequately engaged during transition periods and healthcare professionals often develop discharge plans without consulting them. For patients dependent on caregivers, this leads to discharge plans that often are not feasible for the caregivers to implement or may not include the support services caregivers need to implement care plans.<sup>15</sup>

Included studies noted their rationale for implementing structured communication and family caregiver engagement interventions was a belief that they can help improve clinical outcomes for patients, reduce readmissions, improve self-management knowledge, reduce medication/communication errors and preventable adverse events, reduce caregiver and patient stress, anxiety, and depression, in addition to improving patient/caregiver satisfaction and experience.

Some included studies further described their rationale for implementing specific PSPs. Lion, 2023<sup>34</sup> used a patient navigator intervention to offer culturally



tailored assistance to families from ethnic/racial minority populations, noting that systemic and interpersonal racism can result in communication and system barriers. Huynh, 2017<sup>44</sup> used ICU diaries because they can help patients reconstruct memories about their ICU experience, and improve psychological outcomes after discharge. Diaries included healthcare-related information and instructions for use. They remained at the bedside of the patient during their ICU stay, went with them following discharge, and ICU nurses encouraged patients to bring them for reference in followup appointment. ICU nurses made the initial diary entry and introduced patients/caregivers to the diary. Patients, caregivers, and family members could add entries to the diaries. Gambhir, 2021<sup>43</sup> used family meetings in the ICU to provide a structured intervention to share information with families and allow patients and families to ask questions and express their perspectives in an effort to reduce anxiety, depression, and post-traumatic stress. Peter, 2015<sup>36</sup> used the teach-back method for hospital discharge conversations. They chose teach-back because it was an “easy-to-use effective communication tool.” Finally, Becker, 2021<sup>42</sup> used a multicomponent intervention that incorporated online video vignettes, coaching sessions, and an online parent networking forum for adolescents discharged from residential treatment centers for substance misuse. They noted a need for programs to engage parent caregivers that provide convenient service delivery methods and less burden.

#### **4.2.5 Question 5. What Are the Effectiveness and Unintended Effects of These PSPs?**

Nine studies<sup>20,34-38,42-44</sup> (including 1,554 patients) met our inclusion criteria. **Table 2** provides an overview of the study characteristics. Two studies<sup>37,42</sup> were randomized controlled trials (RCTs; N=82), six studies (N=1,415) used a pre-post comparison,<sup>20,35,36,38,43,44</sup> and one was a single-arm study (N=57).<sup>34</sup>

Five studies<sup>20,34-36,38</sup> focused on hospital discharge:

- Lion, 2023<sup>34</sup> performed a single-arm study in children of the Family Bridge Program, which had 6 primary components delivered by a trained navigator.
- Park-Clinton, 2023<sup>35</sup> performed a pre-post study of a 25-item checklist in adults.
- Peter, 2015<sup>36</sup> performed a pre-post study in adults of a 3-day educational program using teach-back methods.
- Uong, 2021<sup>38</sup> performed a pre-post study in children of the SAFER care framework, which contained prompted questions to ask medical providers.
- Huth, 2023<sup>20</sup> performed a multicomponent, pre-post study using the I-PASS framework for family and provider communication in children with medical complexity.

Three studies<sup>37,43,44</sup> focused on transfers from the intensive care unit (ICU):

- Gambhir, 2021<sup>43</sup> performed a pre-post study in adults of a 30-minute family meeting with a health care team
- Huynh, 2017<sup>44</sup> performed a pre-post study in adults of a diary that remained at bedside for the entire ICU stay
- Torke, 2016<sup>37</sup> performed a randomized trial in adults of a family navigator who conducted meetings and had structured daily contact during the ICU stay.

The final study, Becker 2021,<sup>42</sup> addressed the discharge of adolescents from residential treatment centers. The treatment involved structured parenting education and access to a parent networking forum.

Regarding patient characteristics, five studies included only adult patients,<sup>35-37,43,44</sup> three studies included only child patients,<sup>20,34,38</sup> and one study<sup>42</sup> focused on adolescent patients (aged 12 to 17 years). When reported, mean patient age ranged from 1.7 years to 67 years, and the percentage of female patients ranged from 35 percent to 61 percent. Two studies<sup>37,42</sup> reported the mean age for caregivers which ranged from 42 to 49 years. Three studies<sup>34,37,42</sup> reported caregiver sex/gender which ranged between 54 percent to 87 percent female. Race and/or ethnicity of patients and/or family caregivers was reported in six studies<sup>34,35,37,38,42,43</sup> (see **Appendix B** for additional details).

Specific patient safety practice (PSP) interventions and their duration varied widely and are described below in **Tables 3 to 5** (see **Appendix B** for additional details). Five studies reported patient or caregiver language: one included English-speaking patients and caregivers only,<sup>37</sup> three included English-speaking and Spanish-speaking patients and caregivers,<sup>20,38,42</sup> and one included Spanish-speaking, English-speaking, and Somali-speaking patients and caregivers.<sup>34</sup> The timing of the delivery of interventions also varied: most interventions targeted patients and caregivers during admission and continued interventions after discharge. One study<sup>43</sup> only provided the intervention during the hospital stay (Day 6 of an ICU stay). Another study<sup>20</sup> provided a restructured discharge summary and followup calls to family caregivers after discharge. All study interventions addressed the care transition period regardless of when they were initiated during the admission and discharge process. In the two RCTs and six pre-post studies, the control group received usual care (either as a separate control group or as a pre-period before implementing the intervention); the single-arm study assessed a single group of patients at baseline and after the intervention. Followup ranged from immediately post-intervention or at discharge to 1 year.

**Table 2. Characteristics of included studies**

Study Design (k=study count)	Patient Population (k=study count)	N Allocated	Mean Age	Sex/Gender	Race/Ethnicity
RCT (k=2)	Adolescent (k=1) <sup>37,42</sup>	N=61	Patients: 15.4 years  Caregivers: 55 years	Patients: 51% female  Caregivers: 82% female	Patients: Black/African American: 11% Multiracial: 26% Hispanic/Latinx <sup>a</sup> : 25%  Caregivers: Black/African American: 13% Multiracial/NR: 5% Hispanic/Latinx <sup>a</sup> : 16%
	Adult (k=1) <sup>37,42</sup>	N=26	Patients: 55 years  Caregivers: 49 years	Patients: 58% female  Caregivers: 54% female	Patients: Black/African American: 23% Hispanic/Latinx: 0%  Caregivers: Black/African American: 27% Hispanic/Latinx: 0%
Pre-post (k=6)	Pediatric (k=2) <sup>20,38</sup>	N=587	Patients: 1.7 years in 1 study; median 13 years in 1 study  Caregivers: NR	Patients: 37% female  Caregivers: NR	Patients: Non-Hispanic Black/African American: 29% Non-Hispanic other non-White: 11% Hispanic/Latinx: 43%  Caregivers: NR
	Adult (k=4) <sup>35,36,38,43,44</sup>	N=848 <sup>b</sup>	Patients <sup>c</sup> : 66.7 years  Caregivers: NR	Patients <sup>c</sup> : 54% female  Caregivers: NR	Patients <sup>c</sup> : Black/African American: 53% Other non-White: 8%  Caregivers: NR
Single-arm (k=1)	Pediatric (k=1) <sup>34</sup>	N=60	Patients: 4.4 years  Caregivers: NR	Patients: 35% female  Caregivers: 87% female	Patients: Black/African American: 25% Other non-White: 57% Multiracial: 3% Hispanic/Latinx <sup>a</sup> : 63%  Caregivers: NR

**Abbreviations:** NR = not reported; RCT = randomized controlled trial.

<sup>a</sup> Hispanic/Latinx not mutually exclusive.

<sup>b</sup> Two studies only reported n analyzed, which is included here (n=200 and n=469).

<sup>c</sup> Reported in 2 studies.

#### 4.2.5.1 Risk of Bias

Several types of risk of bias were present in the two included RCTs (**Figure 2; Appendix C, Table C-1**). We rated one RCT as moderate risk of bias,<sup>42</sup> and the other as high risk of bias.<sup>37</sup> The moderate risk of bias trial had unclear randomization techniques, did not report allocation concealment, blinded

outcome assessors but not patients or care providers, and did not report if they used intent to treat analysis, but attrition rates were acceptable. In the high risk of bias trial, groups were not similar at baseline, there was no blinding of patients, caregivers, or outcomes assessors, did not perform intent to treat analysis, and differential attrition between groups was high.

**Figure 2. Risk of bias assessments for randomized controlled trials**

Study	Adequate Randomization	Allocation Concealment	Baseline Similarities	Patients and Personnel Blinding	Outcome Assessor Blinding	ITT Analysis	Acceptable Overall Attrition	Acceptable Differential Attrition	Overall Assessment
Becker, 2021	?	?	✓	✗	✓	?	✓	✓	↔
Torke, 2016	✓	✓	✗	✗	✗	✗	✓	✗	⊠

Legend	
✓	Yes
?	Unclear/NR
✗	No
↔	Moderate ROB
⊠	High ROB

**Abbreviations:** ITT = intention to treat; NR = not reported; ROB = risk of bias.

We rated the six pre-post studies as serious or critical risk of bias (**Figure 3; Appendix C, Table C-2**). Two studies<sup>35,43</sup> had serious risk of bias ratings with major concerns around comparable groups at baseline, ascertainment of exposures and confounders, blinding, and appropriate use of statistical analysis to account for potential confounders. We rated four pre-post studies<sup>20,36,38,44</sup> as critical risk of bias with concerns in all domains for all studies. We also rated the single-arm study<sup>34</sup> as critical risk of bias with concerns in all domains except for reporting attrition and loss-to-followup.

**Figure 3. Risk of bias assessments for nonrandomized studies**

Study	Patient Selection	Baseline Similarities	Accurate Ascertainment of Exposures and Confounders	Outcome Assessor Blinding	Missing Data	No Important LTF	Appropriate Analyses	Outcome Specification and Ascertainment	Overall Assessment
Gambhir, 2021	✓	?	?	✗	✓	✓	?	✓	⊠
Huth, 2023	✗	?	✓	✗	✓	✓	✗	✓	⊠⊠⊠
Huynh, 2017	✗	?	✗	✗	✗	✗	✗	✓	⊠⊠⊠
Lion, 2023	?	---	✗	✗	✓	✓	✗	?	⊠⊠⊠
Park-Clinton, 2023	✓	✗	✗	✗	✓	✗	✗	✓	⊠
Peter, 2015	?	?	✗	✗	✗	?	✗	?	⊠⊠⊠
Uong, 2021	?	✗	✗	✗	✓	✓	✗	✓	⊠⊠⊠

Legend	
✓	Yes
?	Unclear/NR
✗	No
---	NA
⊠	Serious ROB
⊠⊠⊠	Critical ROB

**Abbreviations:** LTF = loss to followup; NA = not applicable; NR = not reported; ROB = risk of bias.

#### 4.2.5.2 Interventions Focused on Hospital Discharge Care Transitions

Four pre-post studies<sup>20,35,36,38</sup> (N=more than 675; sample size not reported in one study) and one single-arm study<sup>34</sup> (n=57) compared relevant PSPs using structured communication with family or informal caregivers for patients following hospital discharge (**Table 3**). Below, we organized study results by pediatric and adult patient populations and summarize their methods and results.

##### 4.2.5.2.1 Interventions focused on Hospital Discharge Care Transitions in Pediatric Populations

Two pre-post studies<sup>38</sup> (N=587) and one single-arm study<sup>34</sup> (n=57) evaluated relevant PSPs in hospitalized pediatric patients; we rated both as critical risk of bias (**Table 3**). Two studies targeted family/parent/informal caregivers and the other specifically targeted parent caregivers.

One critical risk of bias, pre-post study (n=433)<sup>38</sup> compared an intervention called SAFER Care (developed internally) versus usual care. The SAFER Care intervention included standardized worksheets with conversation prompts in Spanish and English and family-liaison meetings with family and informal caregivers of hospitalized general and surgical subspecialty pediatric patients. The study found no statistically significant differences in 7-day or 30-day rates of emergency department (ED) visits or hospital readmissions.

Another critical risk of bias pre-post study (n=154)<sup>20</sup> compared a multimodal intervention that adapted the I-PASS framework to improve communication with families who spoke English or Spanish and between providers of children with medical complexity following discharge from hospital to home. The study used a structured template for followup calls with family members within 24 to 48 hours of hospital discharge and EHR-based, structured templates with outpatient providers to provide hospitalization summaries and medication lists and to assign specific care responsibilities. The study assessed medical error incidents (including medication/communication errors and adverse events) following discharge, 30-day rehospitalization, and 30-day ED visits. Statistically significant differences were found in the rate per discharge of any medical error incident (0.95 [95% CI 0.73 to 1.23] vs. 1.51 [95% CI 1.27 to 1.77], p=0.003), but not in preventable adverse events, nonpreventable adverse events, nonharmful errors, or 30-day rehospitalizations. The study reported a statistically significant reduction in 30-day ED visits when analyzed using the chi-square test (3.4% [2/59] vs. 12.6% [12/95]), but our own chi-square test revealed that the difference was not statistically significant (p=0.052).

The single-arm study<sup>34</sup> used an internally developed intervention called the Family Bridge Program, consisting of 6 components delivered by a trained navigator and assessed caregiver stress using the Perceived Stress Scale-Short Form. The study reported no statistically significant differences between baseline and two to four weeks followup after hospital discharge in caregiver stress. The study included patients who spoke English, Spanish, and Somali in uninsured parent-patient dyads wherein the parent reported or the patient self-reported their ethnicity and race as non-White and non-Hispanic. Subgroup analyses for primarily English-, Somali-, and Spanish-speaking patients also showed no statistically significant differences in caregiver stress.

#### **4.2.5.2.2 Interventions Focused on Hospital Discharge Care Transitions in Adult Populations**

Two studies<sup>35,36</sup> (N=557) compared a preintervention period with a postintervention period and assessed relevant PSPs in hospitalized adult patients; both studies reported 30-day readmissions at different followup times (**Table 3**).

One serious risk of bias study<sup>35</sup> (n=88) compared using a 25-item checklist for targeted discharge planning with usual care for patients discharged from the hospital. There were no statistically significant differences in 30-day readmissions between the 16-week pre-intervention period and the ensuing 16-week post-intervention period. Of note, 35 percent of caregivers were family (i.e., informal) caregivers and 65 percent were home healthcare (i.e., trained, paid) caregivers in this study.

One critical risk of bias study<sup>36</sup> (n=469) used a pre-post study design to evaluate the impact of a teach-back intervention on 30-day hospital readmissions in adults with heart failure. The care team identified “key-learners” as the primary recipient of the intervention, which could include patients or informal caregivers. The study did not report statistical tests, but noted a 12 percent reduction in 30-day hospital readmissions at 1-year followup among patients receiving the teach-back intervention.

**Table 3. Details of studies focused on hospital discharge care transitions**

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcome Measures	Results
Huth, 2023 <sup>20</sup>  <i>Critical Risk of Bias</i>  Pre-post  (n=154)	Pediatric  Children’s hospital to home discharge  Mixed multisystem chronic conditions	<p>A. I-PASS (6 month period): 3 primary components (n=59)</p> <p>Components included:</p> <ol style="list-style-type: none"> <li>1) structured postdischarge telephone call to families 24 to 48 hours after discharge delivered by a nurse</li> <li>2) restructured discharge summary using I-PASS elements including specific action items related to medications, medical equipment and followup needs</li> <li>3) brief written communication from inpatient provider to outpatient providers with assigned responsibilities for specific action items and documented in the EHR at discharge</li> </ol> <p>B. Usual care prior to intervention implementation (6 month period) (n=95)</p> <p>Discharge process included:</p> <ol style="list-style-type: none"> <li>1) Discharge summary of the hospital course faxed to primary care provider</li> <li>2) Families received:               <ol style="list-style-type: none"> <li>a. a brief summary of hospitalization with printed followup instructions</li> <li>b. printed medication list with hand-written updates</li> <li>c. instructions to followup with primary care providers within 48 to 72 hours</li> </ol> </li> </ol>	<ul style="list-style-type: none"> <li>• Postdischarge medical error incidents, AEs and harms</li> <li>• ED visits</li> <li>• Readmissions</li> </ul>	<p><i>A vs. B</i></p> <p>Any postdischarge incident (rate per discharge) 0.95 (95% CI 0.73 to 1.23) vs. 1.51 (95% CI 1.27 to 1.77), p=0.003</p> <p>Nonharmful errors (rate per discharge) 0.54 (95% CI 0.38 to 0.77) vs. 0.79 (95% CI 0.63 to 0.99), p=0.08</p> <p>Total AEs (rate per discharge) 0.10 (95% CI 0.05 to 0.23) vs. 0.23 (95% CI 0.15 to 0.35), p=0.07</p> <p>Preventable AEs (rate per discharge) 0.03 (95% CI 0.01 to 0.14) vs. 0.08 (95% CI 0.04 to 0.17), p=0.33</p> <p>Nonpreventable AEs (rate per discharge) 0.07 (95% CI 0.03 to 0.18) vs. 0.15 (95% CI 0.09 to 0.25), p=0.22</p> <p>30-day ED visit 3.4% (2/59<sup>b</sup>) vs. 12.6% (12/95<sup>b</sup>), RR 0.27 (95% CI 0.06 to 1.16)<sup>b</sup></p> <p>30-Day Rehospitalization 10.2% (6/59<sup>b</sup>) vs. 15.8% (15/95<sup>b</sup>), p=0.32, RR 0.64 (95% CI 0.26 to 1.57)<sup>b</sup></p>

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcome Measures	Results
Lion, 2023 <sup>34</sup>  <i>Critical Risk of Bias</i>  Single-arm Study  (n=57)	Pediatric  Children's hospital stay/discharge  Hospital stay <sup>a</sup>	A. Family Bridge Program: 6 primary components delivered by a trained navigator (n=57)  Components included: 1) orientation to the hospital, unit, room, and hospital resources 2) unmet social needs assessment, followed by connection to appropriate resources 3) communication preference assessment to collect information about family context, preferences, and health literacy 4) communication coaching for parents/caregivers to help them clarify and practice asking questions of the medical team 5) emotional support through daily check-ins while hospitalized 6) Single followup phone call 2 days post-discharge to address remaining questions and connect families to ongoing resources if needed  B. NA	<ul style="list-style-type: none"> <li>Caregiver stress</li> </ul>	<i>Baseline vs. Followup</i>  Perceived Stress Scale - Short Form (mean; 0 to 16 scale, higher scores = more stress): Overall (n=55): 5.0 (SD 2.9) vs. 5.6 (SD 3.2), p=0.25  Subgroup analysis: <ul style="list-style-type: none"> <li>English-speaking patients (n=35): 5.0 (SD 2.9) vs. 5.5 (SD 3.2), p=0.43</li> <li>Somali-speaking patients (n=2): 2 (SD 2.8) vs. 4 (SD 5.7), p=0.50</li> <li>Spanish-speaking patients (n=18): 5.3 (SD 2.9) vs. 5.9 (SD 3.2), p=0.55</li> </ul>



<b>Author, Year</b> <i>Risk of Bias</i> <b>Study Design</b> <b>(n Analyzed)</b>	<b>Patient Population</b> <b>Setting/Care Transition</b> <b>Condition</b>	<b>Description of Intervention (n) and Comparison (n)</b>	<b>Relevant Outcome Measures</b>	<b>Results</b>
Park-Clinton, 2023 <sup>35</sup>  <i>Serious Risk of Bias</i>  Pre-post  (n=88)	Adult  Hospital to home  Hospital stay <sup>a</sup>	A. Targeted discharge planning: 25-item checklist (modified Re-Engineered Discharge toolkit and adapted CMS discharge planning beginning at hospital admission. Discharge planners assisted in coordinating care when unmet needs were identified. (n=30)  B. No targeted discharge planning (n=58)	• Readmissions	<i>A vs. B</i> 30-Day readmissions 3.3% (1/30) vs. 19.0% (11/58), RR 0.18 (95% CI 0.02 to 1.30) <sup>b</sup>
Peter, 2015 <sup>36</sup>  <i>Critical Risk of Bias</i>  Pre-post  (n=unclear)	Adult  Hospital to home  Heart failure	A. Teach-back - 3-day educational conversations using teach-back to engage patients and caregivers delivered during hospitalization in order to enhance discharge planning (n=180)  B. No teach-back (n=289)	• Readmissions	<i>A vs. B</i> 30-day readmissions 7.61% vs. 9.97% (statistical test not reported)  Specifically in the pilot unit the admission rate reduced from 28.2% at baseline to 14% at 1-year followup

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcome Measures	Results
Uong, 2021 <sup>38</sup>  <i>Critical Risk of Bias</i>  Pre-post (n=433)	Pediatric  Pediatric hospital to home  Hospital stay (general pediatric and surgical subspecialty)	A. SAFER Care program (1 year implementation) (n=262)  Components included:  1) worksheets in Spanish and English distributed to caregivers who described the SAFER Care framework and contained prompted questions caregivers should ask medical providers before discharge  2) the worksheet included space for caregivers to write answers  3) family liaison met with caregivers at least once during admission to review the SAFER Care framework and distribute additional worksheets  B. Usual care (4 months directly preceding implementation period) (n=171)	<ul style="list-style-type: none"> <li>• ED visits</li> <li>• Readmissions</li> </ul>	<i>A vs. B</i> 7-day ED visits 1.9% (5/262) vs. 1.8% (3/171), RR 1.09 (95% CI 0.26 to 4.49) <sup>b</sup>  30-day ED visits 9.2% (24/262) vs. 8.2% (14/171), RR 1.12 (95% CI 0.60 to 2.10) <sup>b</sup>  7-day readmissions 0% (0/262) vs. 0.6% (1/171), RR 0.22 (95% CI 0.01 to 5.32) <sup>b</sup>  30-day readmissions 2.7% (7/262) vs. 4.7% (8/171), RR 0.57 (95% CI 0.21 to 1.55) <sup>b</sup>

**Abbreviations:** AE = adverse event; CI = confidence interval; ED = emergency department; EHR = electronic health record; NA = not applicable; RR = relative risk; SD = standard deviation.

<sup>a</sup> Not further specified.

<sup>b</sup> Calculated by review team.

### 4.2.5.3 Interventions Focused on ICU Care Transitions

One small, high risk of bias RCT<sup>37</sup> (n=21) and two pre-post studies<sup>43,44</sup> with serious and critical risks of bias (N=271) assessed relevant PSPs for ICU care transitions in adult patients (**Table 4**). The RCT compared a multicomponent family navigator intervention using structured communication and family meetings with surrogate decision makers in patients with severe cognitive impairment with usual care alone. The RCT assessed caregiver anxiety using General Anxiety Disorder-7 instrument and depression using the Patient Health Questionnaire-9 instrument and found no statistically significant differences at 6- to 8-week followup between groups for either outcome.

The two studies<sup>43,44</sup> evaluating interventions for ICU transfers compared a pre-intervention period with a post-intervention period. One study<sup>43</sup> with serious risk of bias (n=71) compared using 30-minute family meetings with family caregivers versus usual care. The study assessed patient satisfaction with discharge instructions using a 5-point Likert scale on Day 6 of the ICU stay. Patients receiving family meetings were more likely to report being mostly or completely satisfied with discharge instructions (89.7% vs. 57.1%, RR 1.57 (95% CI 1.17 to 2.10)). The other critical risk of bias study<sup>44</sup> (n=200) implemented an ICU diary intervention in adult patients and their family caregivers in the medical/surgical ICU and the cardiovascular ICU at a single institution. ICU nurses encouraged patients and caregivers to bring their diaries to followup appointments after discharge. There were no statistically significant differences in family satisfaction or family decision making at patient discharge. One aim of the study was to increase referrals to a post-ICU clinic and found slightly higher referrals in the intervention group (8.8 referrals per month vs. 5 referrals per month; statistical tests for significance not reported).

**Table 4. Details of studies focused on transfers from intensive care units**

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcomes	Results
Gambhir, 2021 <sup>43</sup>  <i>Serious Risk of Bias</i>  Pre-post  (n=71)	Adult  ICU transfers  ICU stay <sup>a</sup>	A. 30-minute family meeting on day 6 of stay with a health care team to discuss admission reason, condition/test updates, consult service recommendations, plans for procedures (as applicable), patient/caregiver questions about diagnosis, new medication information, discharge plan/disposition, followup plan with primary care and subspecialists, code status/goals of care/healthcare proxy status if applicable (n=29)  B. NR (n=42)	<ul style="list-style-type: none"> <li>• Patient satisfaction of discharge plans<sup>b</sup></li> </ul>	A vs. B Patient satisfaction with discharge instructions: Mostly or Completely Satisfied: 89.7% (26/29) vs. 57.1% (24/42), RR 1.57 (95% CI 1.17 to 2.10) <sup>c</sup>
Huynh, 2017 <sup>44</sup>  <i>Critical Risk of Bias</i>  Pre-post  (n=200)	Adult  ICU transfers  ICU stay: medical/surgical ICU (MICU) and cardiovascular ICU (CICU)	A. ICU Diary intervention (3-month period): Diaries distributed by nurses and stay at bedside for the entire ICU stay and leave with the patient when they are discharged. Daily entries could be written by staff, patients, family members, or friends. Diaries consisted of a 45-page spiral bound notebook with letter to patient/friends/family explaining the diary, space for text/graphical diary entries, list of terms used frequently in the ICU, and a description of the post-ICU recovery program (n=107 [n=48 MICU, n=59 CICU])  B. 3-month period prior to diary intervention (n=93 [n=50 MICU, n=43 CICU])	<ul style="list-style-type: none"> <li>• Family satisfaction</li> <li>• Referrals to post-ICU recovery clinic</li> </ul>	A vs. B Family satisfaction with care (mean, 0 to 100 scale, higher scores = better satisfaction) MICU: 89 vs. 91 CICU: 93 vs. 93 (dispersion not reported)  Family satisfaction with decision making (mean, 0 to 100 scale, higher scores = better satisfaction) MICU: 87 vs. 90 CICU: 92 vs. 90 (dispersion not reported)  Referrals to post-ICU recovery clinic (mean; 4 months post intervention vs. 4 months pre intervention) 8.8 per month vs. 5 referrals per month (dispersion not reported)

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcomes	Results
Torke, 2016 <sup>37</sup>  <i>High Risk of Bias</i>  RCT  (n=21)	Adult  ICU transfers  ICU transfers in patients with severe cognitive impairment	A. Use of a family navigator (n=9):  1) Introductory meeting with caregiver 2) structured daily contact during ICU stay using a structured form to guide daily family communication, including the patient status, goals of care, and clinical plan for the day 3) informational/emotional support modules using an oral script and handouts 4) family meetings to monitor and facilitate understanding of clinical information and provide emotional support using VALUE framework that includes 5 communication behaviors (value, acknowledge, listen, understand, elicit) 5) post-discharge phone calls at 3 days and 2 weeks to assess unmet medical, informational, or emotional needs  B. Usual care (n=12):  1) Support resources available in the ICU 2) ICU social worker providing ongoing, in-depth psychosocial support to all families and coordinated family meetings 3) chaplains available to provide spiritual care	<ul style="list-style-type: none"> <li>Caregiver anxiety</li> <li>Caregiver depression</li> </ul>	<p>A vs. B</p> <p>Caregiver anxiety (mean, GAD-7, 0 to 21 scale, higher scores = greater anxiety) 5.7 (SD 5.7) vs. 3.9 (SD 5.0), p=0.32</p> <p>Caregiver depression (mean, PHQ-9, 0 to 27 scale, higher scores = greater depression) 7.1 (SD 7.4) vs. 4.2 (SD 4.6), p=0.34</p>

**Abbreviations:** CI = confidence interval; CICU = cardiac intensive care unit; ED = emergency department; GAD-7 = Generalized Anxiety Disorder 7-Item; ICU = intensive care unit; MICU = medical intensive care unit; PHQ-9 = Patient Health Questionnaire-9; RCT = randomized controlled trial; RR = relative risk; SD = standard deviation.

<sup>a</sup> Not further specified.

<sup>b</sup> Statistically significant result for benefits.

<sup>c</sup> Calculated by review team.

#### 4.2.5.4 Interventions Focused on Other Care Transitions

One moderate risk of bias RCT<sup>42</sup> (Table 5; N=61) assessed the impact of a program (Parent SMART [Substance Misuse in Adolescents in Residential

Treatment]) for adolescent patients with substance misuse being discharged from short- and long-term residential treatment centers. The study analyzed effects of the intervention on symptom exacerbation (i.e., proportion of days using alcohol, cannabis, and any substance and substance-related problems) and caregiver satisfaction using the Customer Satisfaction Questionnaire. Outcomes were assessed at week 6, week 12, and week 24 following discharge. There were no statistically significant differences between the Parent SMART group and the usual care group in the proportion of days of alcohol use, cannabis use, or any substance use. Parent caregivers reported higher satisfaction with treatment in the Parent SMART group (88% vs. 59%,  $p=0.02$ ).

**Table 5. Details of studies focused on other care transitions**

Author, Year <i>Risk of Bias</i> Study Design (n Analyzed)	Patient Population  Setting/Care Transition  Condition	Description of Intervention (n) and Comparison (n)	Relevant Outcomes	Results
Becker, 2021 <sup>42</sup>  <i>Moderate Risk of Bias</i>  RCT  (Short-term facility: n=37; Long-term facility: n=24)	Adolescent  Residential treatment center to home 1 short-term facility (mean stay 6 to 10 days), 1 long-term facility (mean stay 30 to 45 days)  Substance misuse	A. Parent SMART + usual care: Initiated shortly after admission to residential treatment and continued during the post-discharge period. (Short-term facility: n=19; Long-term facility: n=12)  3 components included: 1) an off-the-shelf, online program called Parenting Wisely 2) up to 4 coaching sessions to reinforce and customize parenting skills 3) a parent networking forum designed to foster connection among parents and serve as a clinical extender  B. Usual care (Short-term facility: n=18; Long-term facility: n=12) included:  1) Approximately 20 to 25 hours of treatment per week including individual and group therapy sessions focused on psychoeducation and skills building following a dialectical behavioral therapy approach 2) medication management with a licensed psychiatrist or nurse practitioner, as needed 3) parent sessions typically included one discharge planning session in the short-term setting and periodic (e.g., weekly to monthly) parent groups in the long-term setting along with recommendations to followup with an outpatient provider	<ul style="list-style-type: none"> <li>• Days drank alcohol</li> <li>• Days used cannabis</li> <li>• Days used any substance</li> <li>• Substance-related problems</li> <li>• Caregiver satisfaction<sup>a</sup></li> </ul>	<p><i>A vs. B</i></p> <p>Proportion days drank alcohol (Time x Condition) RR 0.89 (95% CI 0.65 to 1.23)</p> <p>Proportion days used cannabis (Time x Condition) RR 1.16 (95% CI 0.97 to 1.40)</p> <p>Proportion days used any substance (Time x Condition) RR 1.15 (95% CI 0.97 to 1.36)</p> <p>Substance-related problems (Time x Condition) RR 0.13 (95% CI - 0.39 to 0.13)</p> <p>Caregiver satisfaction (% satisfied, Consumer Satisfaction Questionnaire, "Satisfied with treatment"): 88% vs. 59%, p=0.02</p>

**Abbreviations:** CI = confidence interval; RCT = randomized controlled trial; RR = relative risk; SMART = Substance Misuse in Adolescents in Residential Treatment.

<sup>a</sup> Statistically significant result for benefits.

#### 4.2.5.1 Harms Associated With Relevant PSPs

No studies reported harms or unintentional outcomes specifically related to the interventions. One RCT<sup>42</sup> reported a single study withdrawal in the intervention group, but did not provide a reason.

#### 4.2.6 Strength of Evidence

Our strength of evidence ratings appear in **Table 6** below. Most studies of PSPs across represented care transitions provided insufficient evidence to draw conclusions about their effectiveness with one exception. We found Low strength of evidence that PSPs in residential treatment care transitions improved caregiver satisfaction based on one RCT (N=61).<sup>42</sup>



**Table 6. Strength of evidence ratings**

Care Transition	Outcome	Number of Studies (k)  Participants Analyzed (N)	Main Findings	Study Limitations	Directness	Consistency	Precision	SOE
Hospital Discharge	30-day hospital readmissions	k=4 Pre-post studies <sup>20,35,36,38</sup>  N=1,144	RRs ranged from 0.18 (95% CI 0.02 to 1.30) to 0.57 (95% CI 0.21 to 1.55) in 3 studies; one study reported an effect in the same direction, but did not report statistical tests	Critical	Direct	Consistent	Imprecise	Insufficient
	30-day ED visits	k=2 Pre-post studies <sup>20,38</sup>  N=433	RRs were 0.27 (95% CI 0.06 to 1.16) <sup>a</sup> and 1.12 (95% CI 0.60 to 2.10)	Critical	Direct	Inconsistent	Imprecise	Insufficient
	Caregiver stress	k=1 Single-arm study <sup>34</sup>  N=57	No statistically significant differences in caregiver stress overall: mean on 0 to 16 scale: 5.0 (SD 2.9) vs. 5.6 (SD 3.2), p=0.25  No statistically significant differences in caregiver stress subanalyses by patient language	Critical	Direct	Unknown	Imprecise	Insufficient
	Any postdischarge medical incident <sup>b</sup>	k=1 Pre-post study <sup>20</sup>  N=154	Statistically significant differences in rates of any incident postdischarge (intervention period vs. pre-period): 0.95 per discharge (95% CI 0.73 to 1.23) vs. 1.51 per discharge (95% CI 1.27 to 1.77)	Critical	Direct	Unknown	Precise	Insufficient

Care Transition	Outcome	Number of Studies (k)  Participants Analyzed (N)	Main Findings	Study Limitations	Directness	Consistency	Precision	SOE
	AEs	k=1 Pre-post study <sup>20</sup>  N=154	No statistically significant difference in rates per hospital discharge (intervention period vs. pre-period):  Total AEs: 0.10 per discharge (95% CI 0.05 to 0.23) vs. 0.23 per discharge (95% CI 0.15 to 0.35)  Preventable AEs: 0.03 per discharge (95% CI 0.01 to 0.14) vs. 0.08 per discharge (95% CI 0.04 to 0.17)	Critical	Direct	Unknown	Imprecise	Insufficient
ICU Care Transitions	Caregiver anxiety	k=1 RCT <sup>37</sup>  N=21	No statistically significant differences in mean GAD-7 scores <sup>c</sup> at followup: 5.7 (SD 5.7) vs. 3.9 (SD 5.0), p=0.32	High	Direct	Unknown	Imprecise	Insufficient
	Caregiver depression	k=1 RCT <sup>37</sup>  N=21	No statistically significant differences in mean PHQ-9 scores <sup>d</sup> at followup: 7.1 (SD 7.4) vs. 4.2 (SD 4.6), p=0.34	High	Direct	Unknown	Imprecise	Insufficient
	Family satisfaction	k=1 Pre-post study <sup>44</sup>  N=200	No statistically significant differences in family satisfaction with care or with decision making	Critical	Direct	Unknown	Imprecise	Insufficient
	Patient satisfaction	k=1 Pre-post study <sup>43</sup>  N=71	More patients in the intervention period reported higher satisfaction with discharge instructions than the pre-period: RR 1.57 (95% CI 1.17 to 2.10) <sup>a</sup>	Serious	Direct	Unknown	Precise	Insufficient

Care Transition	Outcome	Number of Studies (k) Participants Analyzed (N)	Main Findings	Study Limitations	Directness	Consistency	Precision	SOE
Other Care Transitions (Residential Treatment Discharge)	Symptom exacerbation	k=1 RCT <sup>42</sup> N=61	No statistically significant differences in proportion of days using alcohol, days using cannabis, days using any substance, or substance-related problems.	Moderate	Direct	Unknown	Imprecise	Insufficient
	Caregiver satisfaction	k=1 RCT <sup>42</sup> N=61	More caregivers were satisfied with treatment in the intervention group (88% vs. 59%, p=0.02)	Moderate	Direct	Unknown	Precise	Low PSP improves caregiver satisfaction

**Abbreviations:** CI = confidence interval; ED = emergency department; GAD-7 = Generalized Anxiety Disorder 7-Item; ICU = intensive care unit; PHQ-9 = Patient Health Questionnaire-9; PSP = patient safety practice; RCT = randomized controlled trial; RR = relative risk; SD = standard deviation; SOE = strength of evidence.

<sup>a</sup> Calculated by review team.

<sup>b</sup> Includes medication errors and provider-to-provider communication errors.

<sup>c</sup> The GAD-7 scale ranges from 0 to 21; higher numbers indicate greater anxiety.

<sup>d</sup> The PHQ-9 scale ranges from 0 to 27; higher numbers indicate greater depression.

## 4.2.7 Question 6. What Are Common Barriers and Facilitators to Implementing These PSPs?

Six studies<sup>35-38,42,44</sup> reported facilitators for implementing PSPs, and two studies<sup>35,44</sup> noted barriers to implementation. **Table 7** provides implementation facilitators and barriers described in the included studies.

**Table 7. Patient safety practice implementation facilitators and barriers**

Author, Year	Implementation Facilitators	Implementation Barriers
Becker, 2021 <sup>42</sup>	<ul style="list-style-type: none"> <li>Using a technology-assisted intervention</li> </ul>	NR
Huth, 2023 <sup>20</sup>	<ul style="list-style-type: none"> <li>Team training on new communication approaches</li> <li>Iterative review of data with regular feedback to inpatient and outpatient care teams</li> </ul>	NR
Huynh, 2017 <sup>44</sup>	<ul style="list-style-type: none"> <li>Support from AACN CSI program</li> <li>Support from hospital administration executives</li> <li>Support from ICU management team</li> <li>Physician encouragement/enthusiasm for program</li> <li>Staff education classes on intervention and implementation</li> <li>Initial positive anecdotal accounts and reports from family members to staff nurses and ICU diary team</li> </ul>	<ul style="list-style-type: none"> <li>Overflow of ICU</li> <li>Decline in ICU diary entries by nurses over time</li> <li>Competing hospital-level priorities</li> </ul>
Park-Clinton, 2023 <sup>35</sup>	<ul style="list-style-type: none"> <li>Starting the patient engagement process at the time of hospital admission</li> </ul>	<ul style="list-style-type: none"> <li>The amount of time it took to complete the patient engagement process</li> </ul>
Peter, 2015 <sup>36</sup>	<ul style="list-style-type: none"> <li>Inclusion of prompts in the EHR to remind hospital nurses to complete teach-back conversation</li> </ul>	NR
Torke, 2016 <sup>37</sup>	<ul style="list-style-type: none"> <li>Data-collection efforts were successful because they included phone and in-person approaches</li> <li>Weekly meetings early in the project with ICU staff encouraged buy-in from clinicians and provided opportunities to troubleshoot problems in real time</li> </ul>	NR
Uong, 2021 <sup>38</sup>	<ul style="list-style-type: none"> <li>PDSA cycles</li> <li>Standardization of discharge information across multiple formats</li> <li>Ease of access to SMART Care framework and use of standardized EHR smartphrases</li> </ul>	NR

**Abbreviations:** AACN CSI = American Association of Critical Care Nurses Clinical Scene Investigator; EHR = electronic health record; PDSA = Plan, Do, Study, Act; ICU = intensive care unit; NR = not reported.

## 4.2.8 Question 7. What Resources (e.g., Cost, Staff, Time) Are Required for Implementation?

Included studies did not provide formal descriptions or analyses of resources required for implementation. All studies except one<sup>43</sup> reported enough information on the intervention for us to ascertain likely resources required for implementation of PSPs.

A variety of resources are required to implement new PSPs. Included studies described pre-implementation time for development or selection of PSPs and materials and a need for structured staff training prior to implementation.

Additionally, designated staff time to complete structured communication approaches, which also impacts overall healthcare delivery team capacity, is required to implement these PSPs. Four studies<sup>36,38,42,44</sup> specifically noted technology-based resources: two studies<sup>36,38</sup> used electronic health records to assist in implementation; one study<sup>44</sup> described using electronic software to distribute surveys and track data; and one study<sup>42</sup> used an available subscription-based online program and created online forums for caregivers to connect. The study provided parent-caregivers with a 6-month subscription to the online program, which likely incurred additional financial costs for implementation. Two studies<sup>34,37</sup> used multicomponent PSPs which included patient navigators. In addition to other required resources described above, these interventions required staff training and expertise to perform the role of a health navigator and additional training for navigators. One additional resource consideration for some PSPs delivered in-person that was not explicitly noted in studies is physical space for structured conversations to occur.

#### **4.2.9 Question 8. What Toolkits Are Available To Support Implementation of These PSPs?**

Although relevant toolkits and related guides exist (see below), only one study used an existing toolkit to implement their PSP. Park-Clinton, 2023<sup>35</sup> modified the Agency for Healthcare Research and Quality's (AHRQ) Re-Engineered Discharge (RED) Toolkit and adapted CMS guidance on hospital discharges to create a 25-item checklist to guide discharge conversations with caregivers. The RED Toolkit<sup>40</sup> provides guidance on conversations to evaluate patients' care capacities concerning medication adherence, access to caregivers at home, visiting physicians, and recognizing anticipated problems.<sup>35</sup>

Peter, 2015<sup>36</sup> did not use a specific toolkit, but adopted questions from IHI's recommendations for ideal transitions for their PSP.<sup>39</sup> This guide provides tips on assessing patient-understanding, using teach-back with patients and caregivers during care transitions, and assessing patient (or caregiver) understanding of instructions. Also, Huth, 2023<sup>20</sup> did not use a particular toolkit, but adopted the I-PASS tool to facilitate communication with family caregivers and outpatient providers. The I-PASS tool, primarily used as a communication tool to enhance patient handoffs between providers, focuses on key aspects of the handoff: (I) illness severity; (P) patient summary; (A) action list; (S) situation awareness and contingency planning; (S) synthesis by receiver.<sup>19</sup>

In addition to toolkits and resources for PSPs included in this review, several general resources using structured approaches to communication with patients and family caregivers exist:

- *AHRQ's Care Transitions from Hospital to Home: IDEAL Discharge Planning Implementation Handbook*<sup>57</sup> which includes guidance on discharge discussions with patients and family caregivers following hospitalization.<sup>57</sup>

- *AHRQ's Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families* which includes strategies for collaboratively creating a safe medication list, teach-backs and other communication tools for patients and caregivers, and warm handoffs.<sup>58</sup>
- *AHRQ's Guide to Patient and Family Engagement in Hospital Quality and Safety* which includes strategies for Patient and Family Advisory Councils, improved communication, teach-back materials and tips, and discharge planning.<sup>59</sup>
- *AHRQ's Toolkit to Engage High-Risk Patients In Safe Transitions Across Ambulatory Settings* which includes checklists for preparing patients and caregivers for new appointments, appointment aides, and a robust set of implementation tools.<sup>60</sup>



## 5. Discussion

### 5.1 Summary and Interpretation of Findings

During and after transitions of care, patients are particularly vulnerable to adverse events, and lack of clear communication with caregivers can increase the risk of harms occurring. Included studies evaluated the effect of PSPs on a variety of outcomes including emergency department (ED) use, hospital readmission, caregiver stress, caregiver anxiety, caregiver depression, symptom exacerbation, and patient/caregiver satisfaction. Many of the interventions we included for Review Questions 5 on benefits and harms of these PSPs used components that allowed clinical providers to listen to caregivers' concerns, assess caregivers' understanding of medical care and discharge instructions, and correct any misunderstandings. Thus, they went far beyond mere one-way patient education. Patient levels of understanding, while necessary for good communication and an important outcome in this field, was outside the scope of this rapid review as it is a surrogate/intermediate outcome, and we focused on direct clinical and patient-related outcomes.

We included nine studies<sup>19,34-38,42-44</sup> conducted in the United States assessing the impact of structured communication with family caregivers during care transitions for hospital, intensive care unit (ICU), and residential treatment care transitions. Studies employed different patient safety practice (PSP) interventions, but all involved a component to structured communication with family caregivers and, in some studies, patients. Unfortunately, they provided insufficient strength of evidence to permit conclusions for most outcomes (see **Table 6** for details). Relevant PSPs improved parent caregiver satisfaction in residential treatment discharge transitions (one study, N=61; SOE: Low).

Included studies did not quantify or detail resource requirements to implement PSPs. The PSPs varied greatly in complexity: some implemented PSPs using a single checklist to guide conversations, while others implemented multicomponent interventions using patient navigators which requires specially trained staff to provide patients and caregivers with support. When healthcare organizations consider implementing these types of interventions, key considerations include sufficient access to materials, staff capacity, and technology requirements.

### 5.2 Limitations

Most studies we included were not designed as research studies and, therefore, have questionable internal validity. Included studies reported on a number of outcomes related to different care transitions, but none reported on medication errors, and there were only three types of transitions of care represented in our included studies (ICU transfers, hospital to home, and residential treatment discharge). Similarly, only one study<sup>42</sup> reported any harms or unintended

consequences related to the PSP, but did not provide a reason. Additionally, four studies used multicomponent interventions,<sup>19,34,37,42</sup> thus making it difficult to determine the effectiveness of individual intervention components. Finally, little evidence exists on the resources required to implement these PSPs (e.g., staff expertise, time requirements).

Because of the rapid nature of this review, we did not use full dual review of abstracts, full-text, or risk of bias assessments, and therefore we may have excluded relevant studies. However, to mitigate this, we were intentionally overly inclusive during our abstract review and used Distiller’s artificial intelligence to identify any “near misses” at the full-text level. A second reviewer also reviewed 30 percent of abstract excludes and the top 10 percent of full text excludes to ensure we comprehensively included relevant studies. Given the rapid nature of this review, we also only included studies conducted in the United States and published in 2010 or later. We excluded nine studies<sup>61-69</sup> that otherwise met inclusion criteria because they were conducted outside of the United States (3 in Iran, 2 in Turkey, and 1 each in China, India, the UK, and Uganda). It is possible some relevant studies were conducted before 2010 (number unknown because the searches only went to 2010). We also did not include outcomes assessing patient or caregiver understanding of care transition instructions.

Finally, it is unclear what constitutes “structured communication,” and no standardized definition exists. We therefore were broadly inclusive of interventions using communication techniques that provided some form of structure with family caregivers (e.g., teach-back, checklists, caregiver education programs, patient-navigator PSPs). We erred on the side of inclusion if studies used a tool to communicate or described a process for communication, but we excluded education-only interventions (e.g., one-way transfers of information) or communication without a tool or formal process. Identifying a standardized definition of “structured communication” would be helpful in order for future research to better compare the effect of related interventions.

### **5.3 Implications for Clinical Practice and Future Research**

Evidence indicates that structured communication practices can improve caregiver satisfaction, but there is insufficient evidence to draw conclusions on other important outcomes. Healthcare organizations looking to implement these PSPs need to consider resource requirements which are difficult to specify and depend on the setting, organization, and existing infrastructure. Using technology-based components may improve access to resources for patients and caregivers and may facilitate implementation of PSPs, but also introduces other challenges to implementation. Team capacity to develop or select specific PSPs and to deliver interventions effectively is another high-priority consideration. Relevant PSPs may also improve outcomes we did not include here. Therefore, it is important for



healthcare organizations to consider their capacity, existing infrastructure, resources required, and targeted goals prior to implementing new structured communication PSPs.

There are a number of future research needs related to these PSPs. First, there is a need for well-designed, adequately powered, randomized controlled trials or prospective nonrandomized controlled studies to assess the effect of these PSPs in different care transitions. Future research also needs to report on additional outcomes, especially medication errors, which were absent in our included studies except for one<sup>19</sup> that combined this outcome with communication errors between providers. Also, future studies should explicitly analyze outcomes related to healthcare disparities and report subgroup analyses for populations who disproportionately experience healthcare disparities. In the context of communication, language proficiency, availability of quality translators—if needed—and healthcare-related literacy and numeracy are important considerations for future research. Further, there is a lack of evidence in published studies related to the resources needed to implement these PSPs, and unintentional harms. Ultimately, implementing structured communication interventions for family caregivers during care transitions is a worthwhile effort and may reduce adverse events, enhance clinical effectiveness, impact care utilization, patient/caregiver satisfaction, and clinician/provider satisfaction.



## 6. References

1. Rosen M, Dy SM, Stewart CM, et al. Final report on prioritization of patient safety practices for a new rapid review or rapid response. Making Healthcare Safer IV. (Prepared by the Johns Hopkins, ECRI, and Southern California Evidence-based Practice Centers under Contract No. 75Q80120D00003). AHRQ Publication No. 23-EHC019-1. Rockville (MD): Agency for Healthcare Research and Quality; 2023 Jul. <https://effectivehealthcare.ahrq.gov/products/prioritization-patient-safety-practices>. Accessed August 4, 2023.
2. Transitions of care. Rockville (MD): Agency for Healthcare Research and Quality; 2016. <https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/carecoordination/measure1.html>. Accessed June 23, 2023.
3. Earl T, Katapodis N, Schneiderman S. 15. Care transitions. In: Hall KK, Shoemaker-Hunt S, Hoffman L, et al, eds. Making Healthcare Safer III: A Critical Analysis of Existing and Emerging Patient Safety Practices AHRQ Pub No 20-0029-EF. Rockville (MD): Agency for Healthcare Research and Quality; 2020.
4. Caregiving for family and friends — a public health issue. Atlanta (GA): Centers for Disease Control and Prevention; 2019. <https://www.cdc.gov/aging/caregiving/caregiver-brief.html>. Accessed June 23, 2023.
5. What is a caregiver? Baltimore (MD): Johns Hopkins Bayview. [https://www.hopkinsmedicine.org/about/community\\_health/johns-hopkins-bayview/services/called\\_to\\_care/what\\_is\\_a\\_caregiver.html](https://www.hopkinsmedicine.org/about/community_health/johns-hopkins-bayview/services/called_to_care/what_is_a_caregiver.html). Accessed June 23, 2023.
6. AARP, National Alliance for Caregiving. Caregiving in the United States 2020. Washington (DC): AARP; 2020
7. Definitions. San Francisco (CA): Family Caregiver Alliance. <https://www.caregiver.org/resource/definitions-0/>. Accessed 2023 Jun 23.
8. Rojas Smith L, Ashok M, Morss Dy S, et al. Contextual frameworks for research on the implementation of complex system interventions. Report no.: 14-EHC014-EF. Rockville (MD): Agency for Healthcare Research and Quality; 2014
9. Sentinel event alert 58: Inadequate hand-off communication. Oakbrook Terrace (IL): The Joint Commission; 2017
10. Naylor MD, Aiken LH, Kurtzman ET, et al. The care span: The importance of transitional care in achieving health reform. Health Aff (Millwood). 2011 Apr;30(4):746-54. doi: 10.1377/hlthaff.2011.0041. PMID: 21471497.
11. Schnipper JL, Fitall E, Hall KK, Gale B. Approach to improving patient safety: communication. PSNet, Agency for Healthcare Research and Quality; 2021 Mar. <https://psnet.ahrq.gov/perspective/approach-improving-patient-safety-communication>. Accessed June 23, 2023.
12. Communication during patient hand-overs. Vol 1, Solution 3. WHO Collaborating Centre for Patient Safety Solutions; 2007. [https://cdn.who.int/media/docs/default-source/patient-safety/patient-safety-solutions/ps-solution3-communication-during-patient-handovers.pdf?sfvrsn=7a54c664\\_8](https://cdn.who.int/media/docs/default-source/patient-safety/patient-safety-solutions/ps-solution3-communication-during-patient-handovers.pdf?sfvrsn=7a54c664_8). Accessed June 23, 2023.
13. Li J, Clouser JM, Brock J, et al. Effects of different transitional care strategies on outcomes after hospital discharge—trust matters, too. Jt Comm J Qual Patient Saf. 2022 Jan;48(1):40-52. doi: 10.1016/j.jcjq.2021.09.012. PMID: 34764025.

14. Becker C, Zumbrunn S, Beck K, et al. Interventions to improve communication at hospital discharge and rates of readmission: A systematic review and meta-analysis. *JAMA Netw Open*. 2021 Aug;4(8):e2119346. doi: 10.1001/jamanetworkopen.2021.19346. PMID: 34448868.
15. Mitchell SE, Laurens V, Weigel GM, et al. Care transitions from patient and caregiver perspectives. *Ann Fam Med*. 2018 May;16(3):225-31. doi: 10.1370/afm.2222. PMID: 29760026.
16. Use the teach-back method: tool #5. Health Literacy Universal Precautions Toolkit, 2nd Edition. Rockville (MD): Agency for Healthcare Research and Quality; 2015 Feb. <https://www.ahrq.gov/health-literacy/improve/precautions/tool5.html>. Accessed June 23, 2023.
17. Yen PH, Leasure AR. Use and effectiveness of the teach-back method in patient education and health outcomes. *Fed Pract*. 2019;36(6):284-9. doi: <https://www.mdedge.com/fedprac/article/202182/health-policy/use-and-effectiveness-teach-back-method-patient-education-and>. PMID: 31258322.
18. For health care providers. What do family caregivers need? Next Step in Care. United Hospital Fund. [https://www.nextstepincare.org/Provider\\_Home/What\\_Do\\_I\\_Need/](https://www.nextstepincare.org/Provider_Home/What_Do_I_Need/). Accessed June 23, 2023.
19. Tool: I-PASS. Agency for Healthcare Research and Quality; 2023. <https://www.ahrq.gov/teamsteps-program/curriculum/communication/tools/ipass.html>. Accessed December 12, 2023.
20. Huth K, Hotz A, Emara N, et al. Reduced Postdischarge Incidents After Implementation of a Hospital-to-Home Transition Intervention for Children With Medical Complexity. *J Patient Saf*. 2023;19(7):493-500. doi: <http://dx.doi.org/10.1097/PTS.0000000000001155>. PMID: 37729645.
21. Priebe S, McCabe R, Bullenkamp J, et al. Structured patient-clinician communication and 1-year outcome in community mental healthcare: cluster randomised controlled trial. *Br J Psychiatry*. 2007 Nov;191:420-6. doi: 10.1192/bjp.bp.107.036939. PMID: 17978322.
22. Priebe S, Kelley L, Omer S, et al. The Effectiveness of a Patient-Centred Assessment with a Solution-Focused Approach (DIALOG+) for Patients with Psychosis: A Pragmatic Cluster-Randomised Controlled Trial in Community Care. *Psychotherapy and Psychosomatics*. 2015;84(5):304-13. doi: <http://dx.doi.org/10.1159/000430991>. PMID: 2015312726, 26278784.
23. Dukhanin V, Dy SM, Sharma S, Vass V, Zhang A, Bass EB, Rosen M. Patient and family engagement. A rapid response. (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 75Q80120D00003). AHRQ Publication No. 23(24)-EHC019-3. Rockville (MD): Agency for Healthcare Research and Quality; October 2023. DOI: 10.23970/AHRQEPC\_MHS4ENGAGE.
24. Evidence-based Practice Centers. Rockville (MD): Agency for Healthcare Research and Quality. <https://effectivehealthcare.ahrq.gov/about/epc>. Accessed September 26, 2023.
25. PSNet. Promoting patient safety. Rockville (MD): Agency for Healthcare Research and Quality; 2023. <https://psnet.ahrq.gov>. Accessed October 11, 2023.
26. Tools. Rockville (MD): Agency for Healthcare Research and Quality; 2023. <https://www.ahrq.gov/tools/index.html>. Accessed October 11, 2023.
27. Bucknall TK, Hutchinson AM, Botti M, et al. Engaging patients and families in communication across transitions of care: An integrative review protocol. *J Adv Nurs*. 2016 Jul;72(7):1689-700. doi: 10.1111/jan.12953. PMID: 26990463.

28. Higgins JP, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*. 2011;343:d5928. doi: <http://dx.doi.org/10.1136/bmj.d5928>. PMID: 22008217.
29. Sterne JA, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ*. 2016;355:i4919. doi: <http://dx.doi.org/10.1136/bmj.i4919>. PMID: 27733354.
30. Higgins JPT, Altman DG, Gøtzsche PC, et al. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*. 2011 Oct;343:d5928. doi: 10.1136/bmj.d5928. PMID: 22008217.
31. Methods guide for effectiveness and comparative effectiveness reviews. AHRQ publication no. 10(14)-EHC063-EF. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2014.
32. Forster AJ, Murff HJ, Peterson JF, et al. The incidence and severity of adverse events affecting patients after discharge from the hospital. *Ann Intern Med*. 2003;138(3):161-7. PMID: 12558354.
33. PCMH benefits to practice clinicians and patients. NCQA PCMH recognition benefits everybody: The practice, clinicians and patients [internet]. Washington (DC): National Committee for Quality Assurance; 2023. <https://www.ncqa.org/programs/health-care-providers-practices/patient-centered-medical-home-pcmh/benefits-support/benefits/>. Accessed October 10, 2023.
34. Lion CK, Arthur KC, García MF, et al. Pilot evaluation of the family bridge program, a communication- and culture-focused inpatient patient navigation program. *Acad Pediatr*. 2023 Jun;S1876-2859(23):00228-0. Online ahead of print. doi: 10.1016/j.acap.2023.06.021. PMID: 37354947.
35. Park-Clinton E, Renda S, Wang F. A targeted discharge planning for high-risk readmissions: Focus on patients and caregivers. *Prof Case Manag*. 2023 Mar;28(2):60-73. doi: 10.1097/NCM.0000000000000591. PMID: 36662660.
36. Peter D, Robinson P, Jordan M, et al. Reducing readmissions using teach-back: Enhancing patient and family education. *J Nurs Adm*. 2015 Jan;45(1):35-42. doi: 10.1097/NNA.000000000000155. PMID: 25479173.
37. Torke AM, Wocial LD, Johns SA, et al. The family navigator: A pilot intervention to support intensive care unit family surrogates. *Am J Crit Care*. 2016;25(6):498-507. doi: <https://doi.org/10.4037/ajcc2016730>. PMID: 27802950.
38. Uong A, Philips K, Hametz P, et al. SAFER care: Improving caregiver comprehension of discharge instructions. *Pediatrics*. 2021 Apr;147(4):e20200031. doi: 10.1542/peds.2020-0031. PMID: 33707198.
39. Nielsen GA, Bartely A, Coleman E, et al. Transforming care at the bedside how-to guide: Creating an ideal transition home for patients with heart failure [internet]. Cambridge (MA): Institute for Healthcare Improvement. <https://www.ihl.org/resources/Pages/Tools/T-CABHowToGuideTransitionHomeforHF.aspx>. Accessed October 11, 2023.
40. Re-engineered discharge (RED) toolkit [internet]. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2013. <https://www.ahrq.gov/patient-safety/settings/hospital/red/toolkit/index.html>. Accessed October 11, 2023.

41. Medicare and Medicaid Programs; Revisions to requirements for discharge planning for hospitals, critical access hospitals, and home health agencies. Washington (DC): Federal Register; 2015. <https://www.federalregister.gov/documents/2015/11/03/2015-27840/medicare-and-medicaid-programs-revisions-to-requirements-for-discharge-planning-for-hospitals>. Accessed October 11, 2023.
42. Becker SJ, Helseth SA, Janssen T, et al. Parent SMART (Substance Misuse in Adolescents in Residential Treatment): Pilot randomized trial of a technology-assisted parenting intervention. *J Subst Abuse Treat*. 2021;127:108457. doi: <http://dx.doi.org/10.1016/j.jsat.2021.108457>. PMID: 34134877.
43. Gambhir HS, Goodrick S, Dhamoon A, Kaul V. Impact of structured and scheduled family meetings on satisfaction in patients admitted to hospitalist service. *J Patient Exp*. 2021 Mar;8:1-5. doi: 10.1177/23743735211002748. PMID: 34179412.
44. Huynh TG, Covalesky M, Sinclair S, et al. Measuring outcomes of an intensive care unit family diary program. *AACN Adv Crit Care*. 2017 Jun;28(2):179-90. doi: 10.4037/aacnacc2017862. PMID: 28592478.
45. Allen J, Lobchuk M, Livingston PM, et al. Informal carers' support needs, facilitators and barriers in the transitional care of older adults: A qualitative study. *Health Expect*. 2022 Dec;25(6):2876-92. doi: 10.1111/hex.13596. PMID: 36069335.
46. Levine C, Feinberg L. Transitions in care: Are they person- and family-centered? *Generations*. 2012;36(4):20-7.
47. Hunt GG, Reinhard SC. The impact of America's changing family upon Federal and State family caregiving policy. *Generations*. 2015 Dec;39(4):73-9.
48. State law to help family caregivers. Washington (DC): AARP. <https://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-2014/aarp-creates-model-state-bill.html#:~:text=In%2042%20states%2C%20the%20District,effect%20or%20will%20be%20soon>. Accessed January 30, 2023.
49. Coleman EA, Roman SP, Hall KA, Min SJ. Enhancing the care transitions intervention protocol to better address the needs of family caregivers. *J Healthc Qual*. 2015 Jan-Feb;37(1):2-11. doi: 10.1097/01.JHQ.0000460118.60567.fe. PMID: 26042372.
50. Reinhard SC, Levine C, Samis S. Home alone: Family caregivers providing complex chronic care. Washington (DC): AARP; 2012 Oct. [https://media.uhfnyc.org/filer\\_public/c5/a6/c5a6c494-42ac-42dd-be0c-99d802e2c985/home\\_alone\\_new\\_final\\_102612.pdf](https://media.uhfnyc.org/filer_public/c5/a6/c5a6c494-42ac-42dd-be0c-99d802e2c985/home_alone_new_final_102612.pdf). Accessed September 27, 2023.
51. Almborg AH, Ulander K, Thulin A, Berg S. Discharge planning of stroke patients: the relatives' perceptions of participation. *J Clin Nurs*. 2009 Mar;18(6):857-65. doi: 10.1111/j.1365-2702.2008.02600.x. PMID: 19239664.
52. Foust JB, Vuckovic N, Henriquez E. Hospital to home health care transition: Patient, caregiver, and clinician perspectives. *West J Nurs Res*. 2012 Mar;34(2):194-212. doi: 10.1177/0193945911400448. PMID: 21427451.
53. Levoy K, Rivera E, McHugh M, et al. Caregiver engagement enhances outcomes among randomized control trials of transitional care interventions: A systematic review and meta-analysis. *Med Care*. 2022 Jul;60(7):519-29. doi: 10.1097/MLR.0000000000001728. PMID: 35679175.

54. Burgdorf JG, Fabius CD, Riffin C, Wolff JL. Receipt of posthospitalization care training among Medicare beneficiaries' family caregivers. *JAMA Netw Open*. 2021 Mar;4(3):e211806. doi: 10.1001/jamanetworkopen.2021.1806. PMID: 33724393.
55. Carbery M, Schwartz S, Werner N, Fields B. Education and skills training for care partners of hospitalised older adults: A scoping review. *Health Educ J*. 2021 Dec;80(8):921-33. doi: 10.1177/00178969211034192. PMID: 37131526.
56. Rodakowski J, Leighton C, Martsof GR, James AE. Caring for family caregivers: Perceptions of CARE Act compliance and implementation. *Qual Manag Health Care*. 2021 Jan-Mar;30(1):1-5. doi: 10.1097/QMH.0000000000000278. PMID: 33229997.
57. Strategy 4: Care transitions from hospital to home: IDEAL discharge planning [internet]. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2013. <https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/strategy4/index.html>. Accessed October 11, 2023.
58. Guide to improving patient safety in primary care settings by engaging patients and families. Rockville (MD): Agency for Healthcare Research and Quality; 2018. <https://www.ahrq.gov/patient-safety/reports/engage/strategies.html>. Accessed October 11, 2023.
59. Guide to patient and family engagement in hospital quality and safety [internet]. Rockville (MD): Agency for Healthcare Research and Quality (AHRQ); 2012. <https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/index.html>. Accessed 2023/10/11.
60. Toolkit to engage high-risk patients in safe transitions across ambulatory settings. Rockville (MD): Agency for Healthcare Research and Quality; 2017. <https://www.ahrq.gov/hai/tools/ambulatory-care/safe-transitions.html>. Accessed October 11, 2023.
61. Bangirana P, Birabwa A, Nyakato M, et al. Use of the creating opportunities for parent empowerment programme to decrease mental health problems in Ugandan children surviving severe malaria: A randomized controlled trial. *Malar J*. 2021 Jun;20(1):267. doi: 10.1186/s12936-021-03795-y. PMID: 34120616.
62. Esmaceli M, Dehghan Nayeri N, Bahramnezhad F, et al. Can addressing family education improve outcomes of patients under home invasive mechanical ventilation? A randomized controlled clinical trial. *Home Health Care Serv Q*. 2023 Jul;42(3):173-92. doi: 10.1080/01621424.2023.2177223. PMID: 37323011.
63. Ng JSK, Chau JPC, Chan AWK, et al. A nurse-led web-based home asthma education program for children and their families: A randomized controlled trial. *J Pediatr Nurs*. 2021 Jul-Aug;59:158-63. doi: 10.1016/j.pedn.2021.04.014. PMID: 33894543.
64. Nia MN, Mohajer S, Bagheri N, Sarboozii-Hoseinabadi T. The effects of family-centered empowerment model on depression, anxiety, and stress of the family caregivers of patients with COVID-19: A randomized clinical trial. *BMC primary care*. 2022 Jul;23(1):185. doi: 10.1186/s12875-022-01795-8. PMID: 35883034.
65. Shahrokhi A, Azimian J, Amouzegar A, Oveisi S. The effect of telenursing on referral rates of patients with head trauma and their family's satisfaction after discharge. *J Trauma Nurs*. 2018 Jul;25(4):248-53. doi: 10.1097/JTN.0000000000000382. PMID: 29985860.

66. Bartik K, Toruner EK. Effectiveness of a preoperative preparation program on children's emotional states and parental anxiety. *J Perianesth Nurs*. 2018 Dec;33(6):972-80. doi: 10.1016/j.jopan.2017.09.008. PMID: 30449445.
67. Staveski SL, Parveen VP, Madathil SB, et al. Parent education discharge instruction program for care of children at home after cardiac surgery in Southern India. *Cardiol Young*. 2016 Aug;26(6):1213-20. doi: 10.1017/S1047951115002462. PMID: 26894411.
68. Suluhan D, Yildiz D, Surer I, et al. Effect of gastrostomy tube feeding education on parents of children with gastrostomy. *Nutrition in Clinical Practice*. 2021 Dec;36(6):1220-9. doi: 10.1002/ncp.10586. PMID: 33047836.
69. Bench S, Day T, Heelas K, et al. Evaluating the feasibility and effectiveness of a critical care discharge information pack for patients and their families: A pilot cluster randomised controlled trial. *BMJ Open*. 2015 Nov;5(11):e006852. doi: 10.1136/bmjopen-2014-006852. PMID: 26614615.

## Authors

Jesse Wagner, M.A., Hanan Aboumatar, M.D., M.P.H., Jonathan R. Treadwell, Ph.D.

## Peer Reviewers

Prior to publication of the final evidence report, the Evidence Based Practice Center (EPC) sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report do not necessarily represent the views of individual reviewers. Peer Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. The AHRQ Task Order Officer (TOO) and the EPC work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

The list of Peer Reviewers follows:

Arti Desai, M.D., M.S.P.H.  
Assistant Professor of Pediatrics  
University of Washington School of Medicine  
Seattle Children's Research Institute  
Seattle, WA

Alisa Khan, M.D., M.P.H.  
Assistant Professor  
Harvard Medical School  
Pediatric Hospitalist  
Boston Children's Hospital  
Boston, MA

## Acknowledgments

The authors gratefully acknowledge the following individuals from the ECRI-Penn Medicine Evidence-based Practice Center: Katherine Donahue and Helen Dunn, B.S., for citation retrieval and management; and Megan Nunemaker M.S.L.S., for conducting the searches for this report.

## Disclaimers

This report is based on research conducted by the Johns Hopkins University under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 75Q80120D00003). The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

**None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.**



The information in this report is intended to help healthcare decision makers—patients and clinicians, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of healthcare services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

This report is made available to the public under the terms of a licensing agreement between the author and the Agency for Healthcare Research and Quality. Most AHRQ documents are publicly available to use for noncommercial purposes (research, clinical or patient education, quality improvement projects) in the United States and do not need specific permission to be reprinted and used unless they contain material that is copyrighted by others. Specific written permission is needed for commercial use (reprinting for sale, incorporation into software, incorporation into for-profit training courses) or for use outside of the United States. If organizational policies require permission to adapt or use these materials, AHRQ will provide such permission in writing.

AHRQ or U.S. Department of Health and Human Services endorsement of any derivative products that may be developed from this report, such as clinical practice guidelines, other quality enhancement tools, or reimbursement or coverage policies, may not be stated or implied.

A representative from AHRQ served as a Contracting Officer's Representative and reviewed the contract deliverables for adherence to contract requirements and quality. AHRQ did not directly participate in the literature search, determination of study eligibility criteria, data analysis, interpretation of data, or preparation or drafting of this report.

AHRQ appreciates appropriate acknowledgment and citation of its work. Suggested language for acknowledgment: This work was based on an evidence report, Engaging Family Caregivers with Structured Communication for Safe Care Transitions: Rapid Review, by the Evidence-based Practice Center Program at the Agency for Healthcare Research and Quality (AHRQ).

**Suggested citation:** Wagner J, Aboumatar H, Treadwell JR. Engaging Family Caregivers with Structured Communication for Safe Care Transitions. (Prepared by the ECRI-Penn Medicine Evidence-based Practice Center under Contract No. Contract No. 75Q80120D00003). AHRQ Publication No. 23(24)-EHC019-12. Rockville, MD: Agency for Healthcare Research and Quality. April 2024. DOI: [https://doi.org/10.23970/AHRQEPC\\_MHS4ENGAGING](https://doi.org/10.23970/AHRQEPC_MHS4ENGAGING). Posted final reports are located on the Effective Health Care Program [search page](#).

## Afterword

Recognized for excellence in conducting comprehensive systematic reviews, the Agency for Healthcare Research and Quality (AHRQ) Evidence-based Practice Center (EPC) Program is developing a range of rapid evidence products to assist end-users in making specific decisions in a limited timeframe. AHRQ recognizes that people are struggling with urgent questions on how to make healthcare safer. AHRQ is using this rapid format for the fourth edition of its Making Healthcare Safer series of reports, produced by the EPC Program and the General Patient Safety Program. To shorten timelines, reviewers make strategic choices about which processes to abridge. However, the adaptations made for expediency may limit the certainty and generalizability of the findings from the review, particularly in areas with a large literature base. Transparent reporting of the methods used and the resulting limitations of the evidence synthesis are extremely important.

AHRQ expects that these rapid evidence products will be helpful to health plans, providers, purchasers, government programs, and the healthcare system as a whole. Transparency and stakeholder input are essential to AHRQ. If you have comments related to this report, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to [MHS@ahrq.hhs.gov](mailto:MHS@ahrq.hhs.gov).

Robert Otto Valdez, Ph.D., M.H.S.A.  
Director  
Agency for Healthcare Research and Quality

Therese Miller, D.P.H.  
Director  
Center for Evidence and Practice Improvement  
Agency for Healthcare Research and Quality

Christine Chang, M.D., M.P.H.  
Director  
Evidence-based Practice Center Division  
Center for Evidence and Practice Improvement  
Agency for Healthcare Research and Quality

David W. Niebuhr, M.D., M.P.H., M.Sc.  
Evidence-based Practice Center Division Liaison  
Center for Evidence and Practice Improvement  
Agency for Healthcare Research and Quality

Craig A. Umscheid, M.D., M.S.  
Director  
Center for Quality Improvement and Patient Safety  
Agency for Healthcare Research and Quality

Margie Shofer, B.S.N., M.B.A.  
Director, General Patient Safety Program  
Center for Quality Improvement and Patient Safety  
Agency for Healthcare Research and Quality

Jennifer Eskandari  
Task Order Officer  
Center for Quality Improvement and Patient Safety  
Agency for Healthcare Research and Quality

Farzana Samad, Pharm.D., FISMP, CPPS  
Health Scientist Administrator  
Center for Quality Improvement and Patient Safety  
Agency for Healthcare Research and Quality

# Appendixes

## Appendix A. Literature Search Strategies

**Table A-1. Search strategy for PubMed**

Set	Query
1	caregiver*[ti] OR "care giver**"[ti] OR carer*[ti] OR caretaker*[ti] OR "care taker**"[ti] OR famil*[ti] OR parent*[ti]
2	discharg*[tw] OR "hospital to home**"[tw] OR (care[tw] AND transition*[tw]) OR (transition*[tw] AND home[tw])
3	communicat*[ti] OR convers*[ti] OR direct*[ti] OR discuss*[ti] OR explain*[ti] OR explan*[ti] OR instruct*[ti] OR "communication aid**"[tw] OR "communication model**"[tw] OR "communication tool**"[tw] OR "structured communication**"[tw]
4	sbar[tw] OR (situation*[tw] AND background*[tw] AND assess*[tw] AND recommend*[tw])
5	"teach back"[tiab:~3]
6	(checklist*[tw] OR "check list**"[tw]) NOT "coreq checklist"[tw]
7	"computer assist**"[tw] OR "computer mediat**"[tw] OR "online assist**"[tw] OR "online mediat**"[tw]
8	((health[ti] OR hospital[ti] OR medical[ti] OR patient[ti]) AND (portal*[ti] OR record*[ti])) OR ehr[ti]
9	#1 AND #2 AND (#3 OR #4 OR #5 OR #6 OR #7 OR #8)
10	#9 NOT ((animal[Title] OR animals[Title] OR canine*[Title] OR dog[Title] OR dogs[Title] OR feline[Title] OR hamster*[Title] OR lamb[Title] OR lambs[Title] OR mice[Title] OR monkey[Title] OR monkeys[Title] OR mouse[Title] OR murine[Title] OR pig[Title] OR piglet*[Title] OR pigs[Title] OR porcine[Title] OR primate*[Title] OR rabbit*[Title] OR rat[Title] OR rats[Title] OR rodent*[Title] OR sheep*[Title] OR swine[Title] OR veterinar*[Title] OR (vitro[Title] NOT vivo[Title])) NOT (human*[Title] OR patient*[Title]))
11	#10 AND english[la]
12	#11 AND (2010:2023[pdat]) AND (("1900/01/01"[Date - Create] : "2023/06/30"[Date - Create]))
13	#12 AND (inprocess[SB] OR publisher[SB] OR pubmednotmedline[SB])
14	#13 AND (retracted[ti] OR retraction[ti] OR withdrawn[ti])

**Table A-2. Search strategy for Embase**

Set	Query
1	'caregiver'/mj OR 'family'/mj OR 'family centered care'/mj OR 'family member'/mj OR 'parent'/exp/mj OR caregiver*:ti OR 'care giver**':ti OR carer*:ti OR caretaker*:ti OR 'care taker**':ti OR famil*:ti OR parent*:ti
2	'care transition'/de OR 'hospital discharge'/exp OR discharg*:ti,ab,kw OR 'hospital to home**':ti,ab,kw OR ((care NEAR/2 transition*):ti,ab,kw) OR ((transition* NEAR/5 home):ti,ab,kw)
3	'interpersonal communication'/mj/exp OR communicat*:ti OR convers*:ti OR direct*:ti OR discuss*:ti OR explain*:ti OR explan*:ti OR instruct*:ti OR ((communication NEXT/1 (aid* OR tool*)):ti,ab,kw) OR 'communication model**':ti,ab,kw OR 'structured communication**':ti,ab,kw
4	sbar:ti,ab,kw OR ((situation* NEAR/5 background* NEAR/5 assess* NEAR/5 recommend*):ti,ab,kw)
5	(teach* NEAR/3 back):ti,ab,kw
6	'checklist'/mj OR ((checklist*:ti,ab,kw OR 'check list**':ti,ab,kw) NOT 'coreq checklist':ab)
7	'computer assisted therapy'/mj OR (((computer OR online) NEXT/2 (assist* OR mediat*)):ti,ab,kw)
8	'medical record'/exp/mj OR (((health OR hospital OR medical OR patient) NEXT/2 (portal* OR record*)):ti) OR ehr:ti
9	#1 AND #2 AND (#3 OR #4 OR #5 OR #6 OR #7 OR #8)

Set	Query
10	#9 NOT ([animals]/lim NOT [humans]/lim OR ((animal:ti OR animals:ti OR canine*:ti OR dog:ti OR dogs:ti OR feline:ti OR hamster*:ti OR lamb:ti OR lambs:ti OR mice:ti OR monkey:ti OR monkeys:ti OR mouse:ti OR murine:ti OR pig:ti OR piglet*:ti OR pigs:ti OR porcine:ti OR primate*:ti OR rabbit*:ti OR rat:ti OR rats:ti OR rodent*:ti OR sheep*:ti OR swine:ti OR veterinar*:ti OR (vitro:ti NOT vivo:ti)) NOT (human*:ti OR patient*:ti)))
11	#10 NOT ('conference paper'/exp OR conference:it OR [conference abstract]/lim OR [conference paper]/lim OR [conference review]/lim OR conference:nc OR congress:nc OR meeting:nc OR proceedings:nc OR sessions:nc OR symposium:nc OR 'conference proceeding':pt)
12	#11 AND [english]/lim
13	#12 AND [2010-2023]/py AND [1-1-1900]/sd NOT [30-06-2023]/sd
14	#13 AND ('retraction notice'/de OR retracted:ti OR retraction:ti OR withdrawn:ti)

**Table A-3. Search strategy for Cochrane Database of Systematic Reviews**

Set	Query
1	[mh Caregivers] OR [mh Family] OR [mh Parents] caregiver*:ti OR (care NEXT giver*):ti OR carer*:ti OR caretaker*:ti OR (care NEXT taker*):ti OR famil*:ti OR parent*:ti
2	[mh "Patient Discharge"] OR [mh "Patient Transfer"] OR (discharg*:ti,ab,kw OR (hosptial NEAR/3 home*):ti,ab,kw OR (care:ti,ab,kw NEAR/2 transition*:ti,ab,kw) OR (transition*:ti,ab,kw NEAR/5 home:ti,ab,kw))
3	#1 AND #2
4	Apply date limit (2010-06/30/2023)

**Table A-4. Search strategy for ECRI Guidelines Trust Database**

Set	Query
#1	(caregiver* OR "care giver*" OR carer* OR caretaker* OR "care taker*" OR famil* OR parent*).mp.
#2	(discharg* OR "hospital to home*" OR (care AND transition*) OR (transition* AND home)).mp.
#3	(communicat* OR convers* OR direct* OR discuss* OR explain* OR explan* OR instruct*).ti. OR ((communication AND (aid* OR tool*)) OR "communication model*" OR "structured communication*").mp.
#4	(sbar OR (situation* AND background* AND assess* AND recommend*)).mp.
#5	(teach* AND back).mp.
#6	(checklist* or "check list*").mp.
#7	((computer OR online) AND (assist* OR mediat*)).mp.
#8	((health OR hospital OR medical OR patient) AND (portal* OR record*)).mp. OR ehr.ti.
#9	1 AND 2 AND (3 OR 4 OR 5 OR 6 OR 7 OR 8)

## Appendix B. Evidence Tables

See accompanying Excel file at <https://effectivehealthcare.ahrq.gov/products/engaging-caregivers-mhs4/rapid-research> for detailed evidence tables of included studies.

## Appendix C. Risk of Bias Assessment

See accompanying Excel file at <https://effectivehealthcare.ahrq.gov/products/engaging-caregivers-mhs4/rapid-research> for risk of bias assessments for included studies.

## Appendix D. List of Excluded Studies With Reasons Upon Full-Text Review

1. Alisic E, Barrett A, Bowles P, et al. Ear for recovery: Protocol for a prospective study on parent-child communication and psychological recovery after paediatric injury. *BMJ Open*. 2015 Feb;5(2):e007393. doi: 10.1136/bmjopen-2014-007393. PMID: 25652805. **Exclusion reason:** Ineligible publication type
2. Amirani L, Namnabati M, Hajiheidari M. Examining the effect of discharge plan on enabling mothers of preterm babies admitted to the neonatal intensive care unit (NICU). *Ann Trop Med Public Health*. 2018;13(Special Issue):SX746. <https://www.atmph.org/>. **Exclusion reason:** Unable to retrieve publication
3. Anderson C, Deepak BV, Amoaateng-Adjepong Y, Zarich S. Benefits of comprehensive inpatient education and discharge planning combined with outpatient support in elderly patients with congestive heart failure. *Congest Heart Fail*. 2005;11(6):315-21. doi: <https://doi.org/10.1111/j.1527-5299.2005.04458.x>. PMID: 16330907. **Exclusion reason:** Ineligible population
4. Ariza-Vega P, Ortiz-Piña M, Mora-Traverso M, et al. Development and evaluation of a post-hip fracture instructional workshop for caregivers. *J Geriatr Phys Ther*. 2020 Jul;43(3):128-36. doi: 10.1519/JPT.000000000000230. PMID: 30913137. **Exclusion reason:** Ineligible study design
5. Balaban RB, Weissman JS, Samuel PA, Woolhandler S. Redefining and redesigning hospital discharge to enhance patient care: a randomized controlled study. *J Gen Intern Med*. 2008;23(8):1228-33. doi: <https://doi.org/10.1007/s11606-008-0618-9>. PMID: 18452048. **Exclusion reason:** Ineligible population
6. Bangirana P, Birabwa A, Nyakato M, et al. Use of the creating opportunities for parent empowerment programme to decrease mental health problems in Ugandan children surviving severe malaria: A randomized controlled trial. *Malar J*. 2021 Jun;20(1):267. doi: 10.1186/s12936-021-03795-y. PMID: 34120616. **Exclusion reason:** Ineligible country
7. Bartik K, Toruner EK. Effectiveness of a preoperative preparation program on children's emotional states and parental anxiety. *J Perianesth Nurs*. 2018 Dec;33(6):972-80. doi: 10.1016/j.jopan.2017.09.008. PMID: 30449445. **Exclusion reason:** Ineligible country
8. Bechtel K, Le K, Martin KD, et al. Impact of an educational intervention on caregivers' beliefs about infant crying and knowledge of shaken baby syndrome. *Acad Pediatr*. 2011 Nov-Dec;11(6):481-6. doi: 10.1016/j.acap.2011.08.001. PMID: 21940233. **Exclusion reason:** Ineligible outcome
9. Becker SJ, Helseth SA, Janssen T, et al. Parent smart: Effects of a technology-assisted intervention for parents of adolescents in residential substance use treatment on parental monitoring and communication. *Evid Based Pract Child Adolesc Ment Health*. 2021;6(4):459-72. doi: 10.1080/23794925.2021.1961644. PMID: 35087933. **Exclusion reason:** Ineligible outcome
10. Bench S, Day T, Heelas K, et al. Evaluating the feasibility and effectiveness of a critical care discharge information pack for patients and their families: a pilot cluster randomised controlled trial. *BMJ Open*. 2015 Nov;5(11):e006852. doi: 10.1136/bmjopen-2014-006852. PMID: 26614615. **Exclusion reason:** Ineligible country

11. Black MD, Vigorito MC, Curtis JR, et al. A multifaceted intervention to improve compliance with process measures for ICU clinician communication with ICU patients and families. *Crit Care Med.* 2013 Oct;41(10):2275-83. doi: 10.1097/CCM.0b013e3182982671. PMID: 24060769. **Exclusion reason:** Ineligible outcome
12. Bloch SA, Bloch AJ. Using video discharge instructions as an adjunct to standard written instructions improved caregivers' understanding of their child's emergency department visit, plan, and follow-up: A randomized controlled trial. *Pediatr Emerg Care.* 2013 Jun;29(6):699-704. doi: 10.1097/PEC.0b013e3182955480. PMID: 23714763. **Exclusion reason:** Ineligible intervention
13. Brett J, Staniszewska S, Newburn M, et al. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ Open.* 2011 Jun;1(1):e000023. doi: 10.1136/bmjopen-2010-000023. PMID: 22021730. **Exclusion reason:** Systematic review/meta-analysis used as source document
14. Bucknall TK, Hutchinson AM, Botti M, et al. Engaging patients and families in communication across transitions of care: An integrative review protocol. *J Adv Nurs.* 2016 Jul;72(7):1689-700. doi: 10.1111/jan.12953. PMID: 26990463. **Exclusion reason:** Ineligible publication type
15. Bucknall TK, Hutchinson AM, Botti M, et al. Engaging patients and families in communication across transitions of care: An integrative review. *Patient Educ Couns.* 2020 Jun;103(6):1104-17. doi: 10.1016/j.pec.2020.01.017. PMID: 32029297. **Exclusion reason:** Background
16. Burgdorf JG, Arbaje AI, Chase JA, et al. Current practices of family caregiver training during home health care: A qualitative study. *J Am Geriatr Soc.* 2022 Jan;70(1):218-27. doi: 10.1111/jgs.17492. PMID: 34618918. **Exclusion reason:** Ineligible study design
17. Cheng L, Zhang Y, Gu Y, et al. Families' readiness for discharge of their pre-term infant: A best practice implementation project. *JBIS Database System Rev Implement Rep.* 2016 Sep;14(9):367-80. doi: 10.11124/JBISRIR-2016-003087. PMID: 27755328. **Exclusion reason:** Ineligible outcome
18. Coleman EA, Parry C, Chalmers S, Min SJ. The care transitions intervention: Results of a randomized controlled trial. *Arch Intern Med.* 2006;166(17):1822-8. doi: <https://doi.org/10.1001/archinte.166.17.1822>. PMID: 17000937. **Exclusion reason:** Ineligible population
19. Coleman EA, Smith JD, Frank JC, et al. Preparing patients and caregivers to participate in care delivered across settings: the Care Transitions Intervention. *J Am Geriatr Soc.* 2004;52(11):1817-25. doi: <https://doi.org/10.1111/j.1532-5415.2004.52504.x>. PMID: 15507057. **Exclusion reason:** Published before 2010
20. Curran JA, Murphy A, Newton M, et al. Discharge instructions for caregivers in the context of pediatric emergency care: A narrative synthesis protocol. *Syst Rev.* 2014 Mar;3:26. doi: 10.1186/2046-4053-3-26. PMID: 24628948. **Exclusion reason:** Ineligible publication type
21. Dabas H, Sharma KK, Joshi P, et al. Video teaching program on management of colostomy: Evaluation of its impact on caregivers. *J Indian Assoc Pediatr Surg.* 2016 Apr-Jun;21(2):54-6. doi: 10.4103/0971-9261.176933. PMID: 27046974. **Exclusion reason:** Ineligible outcome
22. Dang A, Miller S, Horvat D, et al. Assessing post-radiotherapy handover notes from a family physician perspective. *Curr Oncol.* 2018 Feb;25(1):49-52. doi: 10.3747/co.25.3728. PMID: 29507483. **Exclusion reason:** Ineligible population



23. Desai AD, Popalisky J, Simon TD, Mangione-Smith RM. The effectiveness of family-centered transition processes from hospital settings to home: a review of the literature. *Hosp Pediatr*. 2015;5(4):219-31. doi: <http://dx.doi.org/10.1542/hpeds.2014-0097>. PMID: 25832977. **Exclusion reason:** Systematic review/meta-analysis used as source document
24. Devraj AR, Kale AB. "A study to assess the effectiveness of planned teaching regarding home care of PICC-line catheter on knowledge and practices among the mothers of children receiving chemotherapy from selected oncology hospitals of sanglimiraj and kupwad corporation area". *J Cardiovasc Dis Res*. 2021;12(4):870-82. <https://www.jcdonline.org/admin/Uploads/Files/6246c76d630228.06502947.pdf>. **Exclusion reason:** Ineligible outcome
25. Doh J, Hencken L, Mlynarek L, et al. Utilization of a standardized discharge checklist to improve the transition of care for patients receiving parenteral nutrition. *Nutr Clin Pract*. 2021 Aug;36(4):877-83. doi: 10.1002/ncp.10580. PMID: 33037705. **Exclusion reason:** Ineligible population
26. Dorsey BF, Kamimura A, Cook LJ, et al. Communication gaps between providers and caregivers of patients in a pediatric emergency department. *J Patient Exp*. 2022 Jul;9:23743735221112223. doi: 10.1177/23743735221112223. PMID: 35836779. **Exclusion reason:** Background
27. Doucet S, Luke A, Anthonisen G, et al. Hospital-based patient navigation programmes for patients who experience injury-related trauma and their caregivers: A scoping review protocol. *BMJ Open*. 2022 Apr;12(4):e055750. doi: 10.1136/bmjopen-2021-055750. PMID: 35459669. **Exclusion reason:** Ineligible publication type
28. Doucet S, Luke A, Anthonisen G. Hospital-based patient navigation programs for patients who experience injury-related trauma and their caregivers: A scoping review. *BMJ Open*. 2022 Dec;12(12):e066260. doi: 10.1136/bmjopen-2022-066260. PMID: 36572494. **Exclusion reason:** Ineligible intervention
29. Duggleby W, Jovel Ruiz K, Ploeg J, et al. Mixed-methods single-arm repeated measures study evaluating the feasibility of a web-based intervention to support family carers of persons with dementia in long-term care facilities. *Pilot Feasibility Stud*. 2018 Oct;4:165. doi: 10.1186/s40814-018-0356-7. PMID: 30410783. **Exclusion reason:** Ineligible population
30. Duke S, Campling N, May CR, et al. Co-construction of the family-focused support conversation: A participatory learning and action research study to implement support for family members whose relatives are being discharged for end-of-life care at home or in a nursing home. *BMC Palliat Care*. 2020 Sep;19(1):146. doi: 10.1186/s12904-020-00647-5. PMID: 32957952. **Exclusion reason:** Ineligible study design
31. El-Tayar WAA, Mohammed EA, Hassan SES, et al. Discharge plan for parents having children suffering from head trauma. *Indian J Forensic Med Toxicol*. 2021 Oct;15(4):2842-54. doi: 10.37506/ijfmt.v15i4.17133. **Exclusion reason:** Ineligible outcome
32. Esmaeili M, Dehghan Nayeri N, Bahramnezhad F, et al. Can addressing family education improve outcomes of patients under home invasive mechanical ventilation? A randomized controlled clinical trial. *Home Health Care Serv Q*. 2023 Jul;42(3):173-92. doi: 10.1080/01621424.2023.2177223. PMID: 37323011. **Exclusion reason:** Ineligible country
33. Glick AF, Farkas JS, Nicholson J, et al. Parental management of discharge instructions: A systematic review. *Pediatrics*. 2017 Aug;140(2):e20164165. doi: 10.1542/peds.2016-4165. PMID: 28739657. **Exclusion reason:** Considered for other Research Question

34. Halbmeijer NM, Jeukens-Visser M, Onland W, et al. Neurodevelopmental outcomes at two years' corrected age of very preterm infants after implementation of a post-discharge responsive parenting intervention program (TOP Program). *J Pediatr*. 2023;257:113381. doi: 10.1016/j.jpeds.2023.02.025. PMID: 36889631. **Exclusion reason:** Ineligible outcome
35. Hochreiter D, Kuruvilla D, Grossman M, et al. Improving guidance and maternal knowledge retention after well-newborn unit discharge. *Hosp Pediatr*. 2022 Feb;12(2):148-55. doi: 10.1542/hpeds.2021-006307. PMID: 35075487. **Exclusion reason:** Ineligible population
36. Hoek AE, Bouwhuis MG, Haagsma JA, et al. Effect of written and video discharge instructions on parental recall of information about analgesics in children: A pre/post-implementation study. *Eur J Emerg Med*. 2021 Jan;28(1):43-9. doi: 10.1097/MEJ.0000000000000746. PMID: 32842041. **Exclusion reason:** Ineligible intervention
37. Hosseini A, Sharifi N, Dehghanrad F, et al. Effect of telenursing on caregiver burden of care and incidence of some complications in patients with acute stroke discharged from neurological wards: A randomized control trial. *Shiraz E Med J*. 2022 Aug;23(8):e123479. doi: 10.5812/semj-123479. **Exclusion reason:** Ineligible intervention
38. Hwang DY, Yagoda D, Perrey HM, et al. Consistency of communication among intensive care unit staff as perceived by family members of patients surviving to discharge. *J Crit Care*. 2014 Feb;29(1):134-8. doi: 10.1016/j.jcrc.2013.09.009. PMID: 24475496. **Exclusion reason:** Background
39. Jack BW, Chetty VK, Anthony D, et al. A reengineered hospital discharge program to decrease rehospitalization: a randomized trial. *Ann Intern Med*. 2009;150(3):178-87. doi: <https://doi.org/10.7326/0003-4819-150-3-200902030-00007>. PMID: 19189907. **Exclusion reason:** Ineligible population
40. Kagan SH. Using story and art to improve education for older patients and their caregivers. *Geriatr Nurs*. 2018 Jan;39(1):119-21. doi: 10.1016/j.gerinurse.2017.12.008. PMID: 29325718. **Exclusion reason:** Ineligible publication type
41. Knight SW, Trinkle J, Tschannen D. Hospital-to-homecare videoconference handoff: Improved communication, coordination of care, and patient/family engagement. *Home Healthc Now*. 2019 Jul;37(4):198-207. doi: 10.1097/NHH.0000000000000755. PMID: 31274582. **Exclusion reason:** Considered for other Research Question
42. Kolberg K, Larson J, Almeida A, et al. The feasibility of using comic-based concussion discharge instructions gauging likeability and knowledge improvement among adolescents and parents. *Pediatr Emerg Care*. 2021 Dec;37(12):e1603-e10. doi: 10.1097/PEC.0000000000002133. PMID: 32530836. **Exclusion reason:** Ineligible intervention
43. Kyrana E, Beath SV, Gabe S, et al. Current practices and experience of transition of young people on long term home parenteral nutrition (PN) to adult services – A perspective from specialist centres. *Clin Nutr ESPEN*. 2016 Aug;14:9-13. doi: 10.1016/j.clnesp.2016.04.003. PMID: 28531419. **Exclusion reason:** Ineligible population
44. Legg LA, Quinn TJ, Mahmood F, et al. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database Syst Rev*. 2011 Oct(10):CD008179. doi: 10.1002/14651858.CD008179.pub2. PMID: 21975778. **Exclusion reason:** Systematic review/meta-analysis used as source document

45. Leung S, Walgrave M, Barroso J, et al. A communication model to bridge adolescent patients, caregivers, and physicians in transitions of care. *Qual Health Res.* 2021 Jan;31(1):113-21. doi: 10.1177/1049732320957269. PMID: 32930053. **Exclusion reason:** Ineligible study design
46. Lewis SR, Pritchard MW, Schofield-Robinson OJ, et al. Information or education interventions for adult intensive care unit (ICU) patients and their carers. *Cochrane Database Syst Rev.* 2018 Oct(10):CD012471. doi: 10.1002/14651858.CD012471.pub2. PMID: 30316199. **Exclusion reason:** Systematic review/meta-analysis used as source document
47. Lion KC, Kieran K, Desai A, et al. Audio-recorded discharge instructions for limited English proficient parents: A pilot study. *Jt Comm J Qual Patient Saf.* 2019 Feb;45(2):98-107. doi: 10.1016/j.jcjq.2018.06.001. PMID: 30126714. **Exclusion reason:** Ineligible outcome
48. Marston C, Morgan DD, Philip J, et al. Supporting carers as patients move between hospital and home: A systematic review of interventions to support these transitions in care. *J Palliat Med.* 2023 Feb;26(2):270-98. doi: 10.1089/jpm.2022.0221. PMID: 36251853. **Exclusion reason:** Systematic review/meta-analysis used as source document
49. Michelson KN, Clayman ML, Haber-Barker N, et al. The use of family conferences in the pediatric intensive care unit. *J Palliat Med.* 2013 Dec;16(12):1595-601. doi: 10.1089/jpm.2013.0284. PMID: 2013793243, 24175636. **Exclusion reason:** Ineligible outcome
50. Mohamed AF, Soliman N, El-Sayied H, et al. Nursing intervention for caregivers of post autologous bone marrow transplantation patients at home. *Indian J Forensic Med Toxicol.* 2021 Jan;15(1):540-7. doi: 10.37506/ijfmt.v15i1.13462. **Exclusion reason:** Ineligible outcome
51. Mohamed AF, Soliman N, El-Sayied H, et al. Nursing intervention for caregivers of post autologous bone marrow transplantation patients at home. *Medico Legal Update.* 2021 Jan;21(1):112-7. doi: 10.37506/mlu.v21i1.2290. **Exclusion reason:** Ineligible outcome
52. Moore CD, Bernardini GL, Hinerman R, et al. The effect of a family support intervention on physician, nurse, and family perceptions of care in the surgical, neurological, and medical intensive care units. *Crit Care Nurs Q.* 2012 Oct-Dec;35(4):378-87. doi: 10.1097/CNQ.0b013e318268fde3. PMID: 22948372. **Exclusion reason:** Ineligible population
53. Ng JSK, Chau JPC, Chan AWK, et al. A nurse-led web-based home asthma education program for children and their families: A randomized controlled trial. *J Pediatr Nurs.* 2021 Jul-Aug;59:158-63. doi: 10.1016/j.pedn.2021.04.014. PMID: 33894543. **Exclusion reason:** Ineligible country
54. Nia MN, Mohajer S, Bagheri N, et al. The effects of family-centered empowerment model on depression, anxiety, and stress of the family caregivers of patients with COVID-19: A randomized clinical trial. *BMC Prim Care.* 2022 Jul;23(1):185. doi: 10.1186/s12875-022-01795-8. PMID: 35883034. **Exclusion reason:** Ineligible country
55. Parry C, Min SJ, Chugh A, et al. Further application of the care transitions intervention: Results of a randomized controlled trial conducted in a fee-for-service setting. *Home Health Care Serv Q.* 2009;28(2-3):84-99. doi: <https://doi.org/10.1080/01621420903155924>. PMID: 20182958. **Exclusion reason:** Published before 2010

56. Pham TN, Morrison AK, Menard MS, et al. Using comic-based concussion discharge instructions to address caregiver health literacy in the emergency department. *J Emerg Nurs.* 2023 Mar;49(2):236-43. doi: 10.1016/j.jen.2022.12.006. PMID: 36604284. **Exclusion reason:** Ineligible outcome
57. Pierik A, Martins DS, Casey L, et al. Use of instructional videos to reduce central venous catheter complications in children with intestinal failure receiving home parenteral nutrition. *Nutr Clin Pract.* 2021 Aug;36(4):872-6. doi: 10.1002/ncp.10638. PMID: 33624392. **Exclusion reason:** Ineligible intervention
58. Powazki RD, Walsh D. The family conference in palliative medicine: A practical approach. *Am J Hosp Palliat Care.* 2014 Sep;31(6):678-84. doi: 10.1177/1049909113499444. PMID: 24031079. **Exclusion reason:** Ineligible publication type
59. Quenot JP, Meunier-Beillard N, Ecartot F, et al. How can we best organise communication with patients' families? *Anaesth Crit Care Pain Med.* 2018 Jun;37(3):187-9. doi: 10.1016/j.accpm.2018.03.003. PMID: 29578077. **Exclusion reason:** Considered for other Research Question
60. Rabbitt AL, Bretl D, Parker M, et al. Assessment of maternal knowledge and confidence about abusive head trauma and coping with infant crying before and after infant safety education in the neonatal intensive care unit. *J Perinat Neonatal Nurs.* 2018 Oct;32(4):373-81. doi: 10.1097/JPN.0000000000000362. PMID: 30358672. **Exclusion reason:** Ineligible outcome
61. Rodgers C, Bertini V, Conway MA, et al. A standardized education checklist for parents of children newly diagnosed with cancer: A report from the children's oncology group. *J Pediatr Oncol Nurs.* 2018 Jul;35(4):235-46. doi: 10.1177/1043454218764889. PMID: 29589818. **Exclusion reason:** Considered for other Research Question
62. Shahrokhi A, Azimian J, Amouzegar A, et al. The effect of telenursing on referral rates of patients with head trauma and their family's satisfaction after discharge. *J Trauma Nurs.* 2018 Jul;25(4):248-53. doi: 10.1097/JTN.0000000000000382. PMID: 29985860. **Exclusion reason:** Ineligible country
63. Sigalet E, Cheng A, Donnon T, et al. A simulation-based intervention teaching seizure management to caregivers: A randomized controlled pilot study. *Paediatr child health.* 2014 Aug;19(7):373-8. doi: 10.1093/pch/19.7.373. PMID: 25332677. **Exclusion reason:** Ineligible intervention
64. Starks H, Doorenbos A, Lindhorst T, et al. The family communication study: A randomized trial of prospective pediatric palliative care consultation, study methodology and perceptions of participation burden. *Contemp Clin Trials.* 2016 Jul;49:15-20. doi: 10.1016/j.cct.2016.05.004. PMID: 27263074. **Exclusion reason:** Ineligible outcome
65. Staveski SL, Parveen VP, Madathil SB, et al. Nurse and parent perceptions associated with the parent education discharge instruction programme in southern India. *Cardiol Young.* 2016 Aug;26(6):1168-75. doi: 10.1017/S1047951115002164. PMID: 26455596. **Exclusion reason:** Ineligible outcome
66. Staveski SL, Parveen VP, Madathil SB, et al. Parent education discharge instruction program for care of children at home after cardiac surgery in Southern India. *Cardiol Young.* 2016 Aug;26(6):1213-20. doi: 10.1017/S1047951115002462. PMID: 26894411. **Exclusion reason:** Ineligible country
67. Staveski SL, Zhelva B, Paul R, et al. Pediatric cardiac surgery parent education discharge instruction (PEDI) program: A pilot study. *World J Ped Congen Heart Surg.* 2015 Jan;6(1):18-25. doi: 10.1177/2150135114554659. PMID: 25548339. **Exclusion reason:** Ineligible outcome

68. Suluhan D, Yildiz D, Surer I, et al. Effect of gastrostomy tube feeding education on parents of children with gastrostomy. *Nutr Clin Pract*. 2021 Dec;36(6):1220-9. doi: 10.1002/ncp.10586. PMID: 33047836. **Exclusion reason:** Ineligible country
69. Taddio A, MacDonald NE, Smart S, et al. Impact of a parent-directed pamphlet about pain management during infant vaccinations on maternal knowledge and behavior. *Neonatal Netw*. 2014 Mar;33(2):74-82. doi: 10.1891/0730-0832.33.2.74. PMID: 24589898. **Exclusion reason:** Ineligible population
70. Thomas DG, Bradley L, Servi A, et al. Parental knowledge and recall of concussion discharge instructions. *J Emerg Nurs*. 2018 Jan;44(1):52-6. doi: 10.1016/j.jen.2017.04.012. PMID: 28527643. **Exclusion reason:** Ineligible comparator
71. Weis J, Zoffmann V, Greisen G, et al. The effect of person-centred communication on parental stress in a NICU: A randomized clinical trial. *Acta Paediatr*. 2013 Dec;102(12):1130-6. doi: 10.1111/apa.12404. PMID: 23980925. **Exclusion reason:** Ineligible population
72. Wong CI, Desrochers MD, Conway M, et al. Improving home caregiver independence with central line care for pediatric cancer patients. *Pediatrics*. 2023 Apr;151(4):e2022056617. doi: 10.1542/peds.2022-056617. PMID: 36896569. **Exclusion reason:** Ineligible comparator
73. Wood EB, Barnett S, Harrison G, et al. Instrucciones de Alta por Video: Effectiveness of video discharge instructions for Spanish-speaking caregivers in the pediatric emergency department. *J Emerg Nurs*. 2020 Mar;46(2):180-7. doi: 10.1016/j.jen.2019.11.006. PMID: 32019682. **Exclusion reason:** Ineligible outcome
74. Yuen A, Rodriguez N, Osorio SN, et al. Simulation-based discharge education program for caregivers of children with tracheostomies. *Hosp Pediatr*. 2021 Jun;11(6):571-8. doi: 10.1542/hpeds.2020-000984. PMID: 33980665. **Exclusion reason:** Ineligible outcome
75. Yin HS, Dreyer BP, van Schaick L, et al. Randomized controlled trial of a pictogram-based intervention to reduce liquid medication dosing errors and improve adherence among caregivers of young children. *Arch Pediatr Adolesc Med*. 2008;162(9):814-22. doi: <http://dx.doi.org/10.1001/archpedi.162.9.814>. PMID: 18762597. **Exclusion reason:** Published before 2010
76. Zhang X, Gao R, Lin JL, et al. Effects of hospital-family holistic care model on the health outcome of patients with permanent enterostomy based on the theory of 'Timing It Right'. *J Clin Nurs*. 2020 Jul;29(13):2196-208. doi: 10.1111/jocn.15199. PMID: 31970830. **Exclusion reason:** Ineligible population
77. Zheng Y, Anton B, Rodakowski J, et al. Associations between implementation of the caregiver advise record enable (CARE) act and health service utilization for older adults with diabetes: Retrospective observational study. *JMIR Aging*. 2022 Jun;5(2):e32790. doi: 10.2196/32790. PMID: 35727611. **Exclusion reason:** Ineligible intervention

