Parental Management of Discharge Instructions: A Systematic Review

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CONTEXT: Parents often manage complex instructions when their children are discharged from the inpatient setting or emergency department (ED); misunderstanding instructions can put children at risk for adverse outcomes. Parents’ ability to manage discharge instructions has not been examined before in a systematic review.

OBJECTIVE: To perform a systematic review of the literature related to parental management (knowledge and execution) of inpatient and ED discharge instructions.

DATA SOURCES: We consulted PubMed/Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, and Cochrane CENTRAL (from database inception to January 1, 2017).

STUDY SELECTION: We selected experimental or observational studies in the inpatient or ED settings in which parental knowledge or execution of discharge instructions were evaluated.

DATA EXTRACTION: Two authors independently screened potential studies for inclusion and extracted data from eligible articles by using a structured form.

RESULTS: Sixty-four studies met inclusion criteria; most (n = 48) were ED studies. Medication dosing and adherence errors were common; knowledge of medication side effects was understudied (n = 1). Parents frequently missed follow-up appointments and misunderstood return precaution instructions. Few researchers conducted studies that assessed management of instructions related to diagnosis (n = 3), restrictions (n = 2), or equipment (n = 1). Complex discharge plans (eg, multiple medicines or appointments), limited English proficiency, and public or no insurance were associated with errors. Few researchers conducted studies that evaluated the role of parent health literacy (ED, n = 5; inpatient, n = 0).

LIMITATIONS: The studies were primarily observational in nature.

CONCLUSIONS: Parents frequently make errors related to knowledge and execution of inpatient and ED discharge instructions. Researchers in the future should assess parental management of instructions for domains that are less well studied and focus on the design of interventions to improve discharge plan management.

Improving pediatric transitions of care has become a topic of national interest both in terms of improving family-centered care and reducing posthospitalization morbidity. Poor communication between providers and patients and their families can make this transition difficult, leading to suboptimal management of discharge instructions and contributing to postdischarge adverse events. Discharge instructions are often complex and involve multiple domains, including medications, follow-up appointments, concerning symptoms to act on (return precautions), and diet and activity restrictions. Given that discharge plans are complex and patients are at risk for poor outcomes postdischarge, it is important to examine whether patients and families understand and can adequately manage these instructions. Patients often misunderstand or are unable to recall elements of their discharge instructions related to their medications, follow-up appointments, return precautions, and diagnoses after inpatient or emergency department (ED) discharge. Furthermore, patients may have difficulty executing (following or implementing) these instructions; common errors include medication nonadherence and missed follow-up appointments. A majority of work in this field has come from the adult literature, with limited study in pediatrics.

To date, few studies have comprehensively addressed parents’ ability to manage their children’s discharge instructions. Management of discharge instructions in children presents unique challenges compared with those faced by adults managing their own care, including dosing liquid medications and knowing when to return to school. Furthermore, there is a growing population of admitted children with chronic medical problems who are dependent on equipment, increasing discharge plan complexity. Although others have reviewed the inpatient discharge process in general and communication issues among adult and pediatric patients after ED discharge, no authors of a systematic review have examined parental management of inpatient or ED discharge instructions. Our objective with this article is to perform a systematic review of the literature related to parental knowledge and execution of inpatient and ED discharge instructions.

METHODS

The protocol for this review was registered (PROSPERO ID: CRD42015025880) and is available at the following site: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015025880

FIGURE 1
Study flow diagram.15

Literature Search

A medical librarian (J.N.) with training in systematic review methodology searched PubMed/Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, and Cochrane CENTRAL for studies from database inception to January 1, 2017. The search strategy combined keywords and Medical Subject Headings terms for 3 concepts: parents, caregivers, and children; patient discharge, physician instructions, follow-up, and adherence; and inpatient or ED settings. See Supplemental Information for the full search strategy used in PubMed. The first author (A.F.G.) identified additional potential studies through reference tracking of included studies. See Fig 1 for the PRISMA flow diagram.

Study Selection

Studies were eligible for inclusion if they met the following criteria: (1)
RESULTS

Article Selection

Of the 15,863 records identified, there were 9,570 unique studies; their titles and abstracts were screened (Fig 1). A total of 9,412 records were excluded because of lack of relevance on independent review by 2 authors. The remaining 158 articles were screened in full; 99 were excluded (Fig 1). The remaining 59 articles, along with 5 articles identified through reference tracking of included studies, were included in the final analysis.

Risk of Bias

Only 82–35 of the 64 studies had a strong quality rating.27 A majority (n = 39) had a weak rating, whereas 1736–52 had a moderate rating (Table 1). Only 10 studies had a low likelihood of selection bias (individuals likely to be representative of the target population and ≥80% agreed to participate).4 There were only 4 studies for which the authors were clear that outcome assessors were blinded to intervention and exposure status and that study participants were blinded to the research question.32,36,45,46 Only 19 studies had evidence of validity and reliability.† See Supplemental Table 2 for individual components of quality assessment.

original experimental (randomized and nonrandomized interventions) or observational (including cohort, case-control, and cross-sectional) studies; (2) inpatient (including pediatric ward and ICU) or ED settings; and (3) studies in which caregiver (or adolescent) knowledge or ability to execute discharge instructions (overall or related to medications, follow-up appointments, restrictions, return precautions, diagnosis, or equipment [domains initially chosen a priori on the basis of adult literature5–11 and further modified after an initial search]) for children <19 years old related to the reason for the visit were evaluated. To focus our search on parental management of instructions related to the acute issues surrounding their child’s ED visit or hospitalization, we did not include studies in which long-term outcomes (>30 days after discharge) or general disease knowledge were examined or studies from other settings such as the newborn nursery, NICU, outpatient clinic, or psychiatric hospitals, given that these are distinct populations with instructions that may focus on long-term general care, chronic medical issues, or distinct problems; readmissions from these settings may not be related to the discharge diagnosis.16–24 Studies in which researchers examined unplanned postdischarge visits (eg, readmissions, ED visits) without also specifically assessing knowledge or execution of discharge instructions were also excluded. We also excluded review articles, commentaries and editorials, and proposals for new studies as well as studies with a focus primarily on adults (>50% of patients >18 years old), provider outcomes, analyses of discharge instructions themselves (eg, content, readability), and patient opinions and/or satisfaction, because these were not original studies assessing pediatric discharge plan knowledge or execution. Conference abstracts were excluded (there was already a large volume of studies being screened), and studies in which researchers examined outcomes that were measured after multiple admissions (which allows for multiple sets of instructions and an unclear time line of what instructions were given when) were also excluded.

In accordance with Cochrane25 and Agency for Healthcare Research and Quality26 guidelines for selection of studies for inclusion, we followed a 2-step screening process to reduce bias. Two authors (A.F.G. and either J.S.F., C.B., T.S., N.G., or H.S.Y.) independently screened the titles and abstracts of studies identified in the literature search for potential relevance on the basis of the screening criteria by using a web-based tool (Covidence systematic review software; Veritas Health Innovation, Melbourne, Australia. Available at: www.covidence.org). A third author from the above group resolved any disagreements. For records identified as potentially relevant in the initial screen, full-text articles were reviewed by the same group of 2 independent authors (with the third author resolving disagreements); eligibility was determined by using the above-mentioned screening criteria. Full-text articles written in a language other than English were translated into English by a native speaker.

Data Extraction, Assessment of Quality, and Risk for Bias

Data related to study characteristics (first author, year, country, language), study design, methods, parent and child characteristics, and outcomes were independently extracted and summarized by 2 authors (A.F.G. and either M.F. or J.S.F.) using a structured form. Studies were categorized by domain (medications, follow-up appointments, return precautions, restrictions, diagnosis, equipment, general instructions [evaluating overall management without a specific domain mentioned]) and type of management (knowledge or execution). These authors also independently assessed risk of bias for each study by using the Quality Assessment Tool for Quantitative Studies, developed by the Effective Public Health Practice Project; this tool assesses selection bias, study design, confounders, blinding, validity and reliability of collection tools, and subject withdrawals. These component ratings were used to assign a global rating (strong = 0 weak components, moderate = 1 weak component, weak = ≥2 weak components).27 Cases of disagreement were resolved by a consensus discussion and by a third reviewer if necessary.
Characteristics of Included Studies

Studies were conducted between 1985 and 2016. There were 48 ED and 16 inpatient studies. Twenty-five were prospective cohort studies, 18 were randomized controlled trials, 8 were nonrandomized controlled clinical trials, 65,72,79,83,86–89 6 were cross-sectional studies, 53,54,82,90,91 4 were retrospective cohort studies, 28,29,37,41 2 were quality improvement studies, 55,70 and 1 was a case-control study. 34 Knowledge was examined in 20 studies, whereas execution of instructions was examined in 48 (some studies had >1 category that was examined; see Table 1). One article, published in Chile, was written in Spanish. 54 The remaining articles were written in English; 73% of all studies were performed in the United States. Other studies were performed in Canada, 33,36,38,52,57,69,86 Israel, 82,83 Australia, 59 Rwanda, 39 Taiwan, 89 India, 79 Uganda, 87 Saudi Arabia, 53 and Switzerland. 65

In the following sections, studies will be summarized by domain of care. Table 1 summarizes pertinent information about these studies, while Supplementation Table 3 provides more detailed information.

Medications (28 Studies)

Medication knowledge was assessed in 11 studies. 1 Researchers for many studies assessed knowledge of multiple subdomains of medication instructions (eg, dose, frequency, duration) as a conglomerate outcome, 49,54,61,82,83 whereas researchers for 1 study assessed whether parents were aware if a change was made to the medication regimen. 56 The percent of parents with accurate subdomain-specific knowledge varied on the basis of the study and specific subdomain: 62% to 94% knew the correct medication dose, 50,53,65,81,90 58% to 94% frequency, 50,53,65,81 24% to 87% name, 50,53,61 34% to 65% duration, 53,65 70% to 91% indication, 50,65 and 47% side effects. 53

Studies in which execution of medication instructions was assessed fell into 2 categories: medication dosing or adherence. Researchers for 4 ED (and no inpatient) studies examined medication dosing by using an observed dosing assessment. 50,75,90,91 Between 42% and 48% of parents made errors in dosing prescription medications, 50,90,91 whereas 32% to 40% dosed as-needed medications incorrectly 50,75; errors were defined as >20% deviation from prescribed dose 50,90,91 or dose outside of dose range specified on a provided standardized chart. 75 In 1 study, dosing errors were reduced among parents when they received an intervention focused on provider demonstration of measurement of liquid medications and teach-back (specifically “show-back”), facilitated by health literacy–informed, pictogram-based instruction sheets. 50

Researchers who studied medication adherence focused on prescription pickup rates, parental report of medication adherence, and dose counters. Parents failed to pick up prescriptions 7% to 37% of the time. 37,38,58,69,74,81,84,85 Parental report of nonadherence to medications ranged between 21% and 38% (nonintervention groups); errors were defined on the basis of self-reported adherence scales or by counting the number of doses parents reported giving. 50,59,62,78 Researchers for 2 studies examined medication adherence by using more objective methods, including electronic pill box monitoring and a dose counter. 36 Improved adherence was seen with interventions involving standardized printed instructions, 36 a physician dosing demonstration and observed dosing, 52 and tailored education sessions. 51

Variables associated with more medication errors included having multiple medications, 61,81 limited English proficiency, 75,90 older child age, 37,38,59,78 and public or no insurance. 37,81,84

Follow-up Appointments (34 Studies)

Researchers for 3 studies assessed knowledge of follow-up appointment instructions, 53,56,61 with up to 64% of parents not being aware of important follow-up information. 53

Researchers for 32 studies examined rates of follow-up appointment attendance (by parental report or electronic medical record review). 55 Between 28% and 62% of families missed appointments after inpatient discharge. 51,55,70,71 Between 16% and 81% of patients missed follow-up appointments after ED visits. 55 Factors associated with and/or barriers identified by parents to missed follow-up appointments included a diagnosis of low acuity (parental report or diagnoses predefined by authors), 73,27,84,85 having public or no insurance, 4,14,34,85 being of a minority race/ethnicity, 42,63 having an older child, 61,71 being non-English speaking, 42,85 and having school or work conflicts. 31,73 Rates of missed appointments were reduced when appointments were made for patients before discharge 10,44,70 or when follow-up phone calls reminding them of the appointment were conducted. 44,45,58,70

Return Precautions (8 Studies)

Researchers for 8 studies (2 inpatient 33,79 and 6 ED 49,53,64,72,80,86) examined parental management of return precaution instructions. Between 70% and 94% of parents did not recognize important signs and symptoms consistent with their child’s diagnosis. 49,53,80 Return precaution knowledge was higher when a discharge facilitator helped

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1Refs 31,38–40,42,45,52,56,57,59,60,63,66–69,71,73–75,77,78,80,84,85
2Refs 30,32,33,35,36,44–51,58,62,64,76,81
3Refs 49,50,53,54,56,61,65,81–83,91

**Refs 28–32,34,35,40–47,51,55,57,58,60,61,67,70,71,73–76–78,84,85,88,88
†††Refs 28–32,40–47,57,58,60,61,73–76–78,84,85,88
General, medications
Follow-up appointments
QI
Inpatient
Overall missed follow-up appointment rates (within 1 wk of discharge) decreased from 31% to 10% (interventions included a new EMR, documentation reminders, asthma education, and evaluating physician protocol adherence)
Weak

Bhansali et al54
Medications, follow-up appointments
Prospective cohort study
Inpatient
Within 24 h of discharge, 86% knew if new medicines were added, 93% if home medicines stopped, 89% if they needed PCP follow-up, 88% if needed follow-up with other doctors
Weak

Bloch and Bloch18
General
RCT
ED
Use of video discharge instructions led to higher knowledge (all caregivers and gastroenteritis or fever subgroups) compared with written discharge instructions alone (at discharge and 2–5 d later)
Moderate

Cabana et al28
Follow-up appointments
Retrospective cohort study
ED
Sixty-six percent did not attend outpatient asthma visits ≤30 d after index ED visit. Seventeen percent had repeat asthma ED visits in 1 y. Outpatient asthma visit attendance predicted increased rates of repeat ED visits (RR 1.8, 95% CI 1.2–2.7)
Strong

Camp et al17
Follow-up appointments
Prospective cohort study
ED
Thirty percent did not attend an appointment within 2 wk of discharge
Weak

Chande and Exum58
Follow-up appointments, medications
RCT
ED
Parents who received reminder phone calls were more likely to make follow-up calls to their PCP (10–20 d after discharge) compared with controls (90% vs 52% if on medical assistance, P < .001; 80% vs 72% if commercial insurance, P = .02). No significant difference in prescription filling between intervention and control groups (89% vs 88%; P = .05)
Weak

Cheng et al59
Medications
Prospective cohort study
ED
Thirty-two percent did not adhere to use of inhaler with spacer (assessed 1–8 wk after discharge). Younger age, spacer use in hospital, information sheet given, and use of small device were associated with adherence
Weak

Ducharme et al60
Medications
RCT
ED
Overall fluticasone MDI nonadherence worsened from 10% on day 1 to 50% at 2 wk and 70% 4 wk postdischarge. Caregivers given an asthma action plan (intervention) had higher adherence (16% unadjusted, 20% adjusted) compared with controls over days 15–28 after discharge. There were higher rates of filling prescriptions for inhaled corticosteroids within 48 h of discharge in the intervention compared with the control group (RR 1.3, 95% CI 1.1–1.6)
Moderate

Finkelstein et al60
Follow-up appointments
Prospective cohort study
ED
Twenty percent did not attend follow-up appointments within 1 wk of discharge. Reasons for missed appointments included problem resolved, appointment availability, or costs
Moderate

Fosarelli et al61
Follow-up appointments
Retrospective cohort study
ED
Thirty-nine percent missed follow-up appointments (time frame not discussed). More missed appointments to clinic compared with ED (41% vs 11%; P < .001). Higher adherence was associated with urgent visits, temperature <39°C, diagnosis of trauma, private insurance, and infant and school-aged children (reference children 1.5–5.5 y)
Moderate

Gagnon et al62
Restrictions
Prospective cohort study
Inpatient
Twenty percent and 33% of the subjects with mild traumatic brain injury were nonadherent to activity restrictions at 1 and 4 wk postinjury, respectively. Children with mild traumatic brain injury had lower energy expenditure scores compared with controls
Moderate

Gregor et al60
Follow-up appointments
Prospective cohort study
ED
Fifty-five percent did not follow-up with PCP within 4 d of discharge. Eleven percent returned to the ED within 2 mo of discharge. Those adherent to follow-up were more likely to have a subsequent ED visit (aOR 3.0, 95% CI 1.3–6.8)
Weak

Grover et al63
Diagnosis, medications, follow-up appointments
Cross-sectional study
ED
At discharge, 70% recalled diagnosis. Twenty-four percent recalled medication names, 38% knew how to administer medications (dose, frequency, duration of therapy). Fifty percent recalled appointments; 55% kept appointments.
Weak

Henderson and Gagnon64
General, medications
Prospective cohort study
ED
Sixty-eight percent knew their medications and precautions at discharge, 65% at 1 wk.
Strong

Haynes et al65
Follow-up appointments
Prospective cohort study
ED
Sixty-four percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Hodges et al66
Medications
Prospective cohort study
ED
Thirty-eight percent missed follow-up appointments (time frame not discussed).
Weak

Johansson et al67
Follow-up appointments
Prospective cohort study
ED
Twenty percent did not attend follow-up appointments within 1 wk of discharge
Weak

Kane et al68
Medications
Prospective cohort study
ED
Seventy percent of subjects did not follow-up with PCP (P = .03). More missed appointments to clinic compared with ED (41% vs 11%)
Moderate

Kransdorf et al69
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Kushelnikov et al70
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Leung et al71
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Parr et al72
Follow-up appointments
Prospective cohort study
ED
Twenty percent did not attend follow-up appointments within 1 wk of discharge
Weak

Qureshi et al73
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Rabin et al74
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Schachter et al75
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Sheikh et al76
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Sussman et al77
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Tabouli et al78
General, medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Vainer et al79
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Vanderbilt et al80
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Waye et al81
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Ye et al82
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Zaleznik et al83
Medications
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

Zweig et al84
Follow-up appointments
Prospective cohort study
ED
Sixty-eight percent of patients had a recent appointment within 1 wk after discharge. Eighty percent had previous knowledge of medication precautions
Weak

*Please note: The table is not shown in the image, but the following text is provided: “TABLE 1: Study Characteristics”


**Domain(s)** Medications, follow-up appointments, return precautions, General, medications, Follow-up appointments

**Study Design** Cross-sectional study, Inpatient

**Setting** ED

**Key Findings** At follow-up (time frame not discussed), 58% knew medication names, 80% dose, 68% frequency, 65% duration, 47% side effects, 36% plan for follow-up, 41% problems of follow-up symptoms, 38% signs and symptoms of revisit. Written and verbal discharge instructions (compared with verbal instructions alone) were typically associated with higher knowledge, although only statistically significant for side effects (P < .05)

**Quality** Weak
<table>
<thead>
<tr>
<th>Citation</th>
<th>Domain(s)</th>
<th>Study Design</th>
<th>Setting</th>
<th>Key Findings</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemphill et al&lt;sup&gt;44&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Missed appointment rate (within 3 d of discharge) was higher when parents had to arrange their own appointments versus having appointments arranged for them (33% vs 8%; OR 2.5, 95% CI 1.1–5.3). Hispanic ethnicity, non-English speaking, and follow-up recommended &gt;1 d after ED discharge predicted missed appointments</td>
<td>Moderate</td>
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<tr>
<td>Hussain-Rizvi et al&lt;sup&gt;63&lt;/sup&gt;</td>
<td>Medications</td>
<td>RCT</td>
<td>ED</td>
<td>Adherence (giving home albuterol with MDI and spacer) error rates (assessed 2 wk after discharge) were lower in the intervention (observed administering albuterol with MDI in ED after demonstration) versus the control group (albuterol was administered in ED by physician via nebulizer) (5% vs 28%; P = .04)</td>
<td>Weak</td>
</tr>
<tr>
<td>Hwang et al&lt;sup&gt;65&lt;/sup&gt;</td>
<td>Restrictions</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Of children with concussion who resumed regular activities 2 wk postdischarge, 35% were still symptomatic, 58% did not receive medical clearance, and 13% skipped rehabilitation stages. Of subjects who resumed regular activities at 4 wk postdischarge, 23% were still symptomatic, and 46% did not receive medical clearance.Thirty-nine percent returned to play the day of injury against recommendation</td>
<td>Weak</td>
</tr>
<tr>
<td>Isaacman et al&lt;sup&gt;66&lt;/sup&gt;</td>
<td>Medications, return precautions</td>
<td>RCT</td>
<td>ED</td>
<td>Medication knowledge at discharge was higher in those receiving the full intervention (standardized verbal instructions and plain language handout) compared with nonstandardized instructions (control) (90% vs 77%; P &lt; .05) but not significantly different (85%) than the partial intervention group (standardized verbal instructions only). Recall of return precautions was higher in the full intervention (38%) and partial intervention (32%) groups compared with the control (6%) group (P &lt; .05)</td>
<td>Moderate</td>
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<tr>
<td>Ismail et al&lt;sup&gt;64&lt;/sup&gt;</td>
<td>General, return precautions</td>
<td>RCT</td>
<td>ED</td>
<td>At discharge, significantly higher knowledge scores were seen in the intervention (video discharge instructions) compared with the control (verbal and written instructions) group (89% vs 76%; P &lt; .0001)</td>
<td>Weak</td>
</tr>
<tr>
<td>Jamai et al&lt;sup&gt;64&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Case-control study</td>
<td>ED</td>
<td>Thirty-two percent did not attend appointments within 14 d of discharge. Application of splint in the ED was associated with appointment attendance (aOR 2.0, 95% CI 1.3–2.9); older child age was associated with missed appointments (aOR 0.90, 95% CI 0.88–0.97)</td>
<td>Strong</td>
</tr>
<tr>
<td>Jenkins et al&lt;sup&gt;33&lt;/sup&gt;</td>
<td>General, return precautions</td>
<td>RCT</td>
<td>Inpatient</td>
<td>At first follow-up visit (time frame not discussed), there were higher knowledge scores in the intervention (received discharge teaching book) compared with the control (did not receive book) group across categories of general care (0.79 vs 0.73, P &lt; .05). The intervention did not improve return precaution knowledge. Lower scores were seen in American Indians, older patients, patients with a higher number of siblings, nonnative English speakers, and patients with &lt;10% of body with burn</td>
<td>Strong</td>
</tr>
<tr>
<td>Jones et al&lt;sup&gt;65&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Sixteen percent did not attend follow-up appointments (time frame not discussed). The group who missed appointments had significantly higher proportion of children of minority race (82% vs 42%) and who were city residents (91% vs 48%) and a lower proportion of children &lt;8 y old (0% vs 41%) and who had health insurance (0% vs 37%; all P &lt; .05)</td>
<td>Moderate</td>
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<td>Kaestli et al&lt;sup&gt;55&lt;/sup&gt;</td>
<td>Medications</td>
<td>Controlled clinical trial</td>
<td>ED</td>
<td>Parents in the intervention (drug information leaflets written in plain language) had higher levels of medication knowledge (within 72 h of discharge) versus control (no intervention) for dose (89% vs 62%), frequency (86% vs 58%), duration (67% vs 34%), and indication (95% vs 70%; all P &lt; .0001)</td>
<td>Weak</td>
</tr>
<tr>
<td>Kajioka et al&lt;sup&gt;37&lt;/sup&gt;</td>
<td>Medications</td>
<td>Retrospective cohort study</td>
<td>ED</td>
<td>Parents failed to fill 55% of prescriptions within 20 d of discharge (93% of those who filled prescriptions did so within 1 d). Prescription pickup rates were higher in the younger (versus older) children (75% vs 55%; P &lt; .001; OR 2.4, 95% CI 1.6–3.7), boys (versus girls) (69% vs 57%; P = .01, OR 1.7, 95% CI 1.1–2.6), and for private insurance (versus Medicaid) (68% vs 57%; P = .03, OR 1.6, 95% CI 1.1–2.5)</td>
<td>Moderate</td>
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<tr>
<td>Komoroski et al&lt;sup&gt;44&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>RCT</td>
<td>ED</td>
<td>Rates of missed appointments (time frame not discussed) were lower (48%) in the intense intervention group (given appointment, written reminder, work excuse, transportation assistance, discussion of child care arrangements, phone number verified, reminder phone call) and the group given an appointment and written reminder (53%) as compared with the control (78%) group (both P &lt; .001)</td>
<td>Moderate</td>
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</table>
TABLE 1 Continued

<table>
<thead>
<tr>
<th>Citation</th>
<th>Domain(s)a</th>
<th>Study Design</th>
<th>Setting</th>
<th>Key Findingsb</th>
<th>Qualityc</th>
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<tr>
<td>Kun and Warburton&lt;sup&gt;66&lt;/sup&gt;</td>
<td>Equipment</td>
<td>Prospective cohort study</td>
<td>Inpatient</td>
<td>Knowledge scores for individual types of equipment (assessed 48 h after discharge) ranged from 50% to 100%, with lowest scores for operation and maintenance for total parenteral nutrition (50%), vendor information for tracheostomy care (50%), and basic knowledge of treatment of gastrostomy tubes (54%). Knowledge levels scores were at 100% in all areas for Broviac care and apexa monitoring. Average knowledge scores were low (65%–75%) for parents of children with multiple home care treatments.</td>
<td>Weak</td>
</tr>
<tr>
<td>Lerret and Weiss&lt;sup&gt;57&lt;/sup&gt;</td>
<td>Follow-up appointments, medications</td>
<td>Prospective cohort study</td>
<td>Inpatient</td>
<td>Readiness for hospital discharge (assessed at discharge) was significantly associated with improved follow-up appointment adherence but not adherence difficulty with medications.</td>
<td>Weak</td>
</tr>
<tr>
<td>Lerret et al&lt;sup&gt;68&lt;/sup&gt;</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>Inpatient</td>
<td>Readiness for discharge (assessed at discharge) was not significantly correlated with medication adherence 3 wk postdischarge.</td>
<td>Weak</td>
</tr>
<tr>
<td>Liberman et al&lt;sup&gt;23&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Retrospective cohort study</td>
<td>ED</td>
<td>Seventy-six percent missed follow-up appointments within 7 d of discharge (range: 62% in children with pneumonia to 89% in patients with asthma ages 7–12); 60% missed appointments within 30 d.</td>
<td>Strong</td>
</tr>
<tr>
<td>Matsui et al&lt;sup&gt;69&lt;/sup&gt;</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Parents failed to fill 7% of prescriptions within 1 d of discharge. Parents failed to fill 7% of prescriptions; 27% felt the prescription was unnecessary. Only dissatisfaction with explanation of the medical problem predicted nonadherence (aOR 2.3, 95% CI 1.2–4.5, <em>P</em> = .01).</td>
<td>Weak</td>
</tr>
<tr>
<td>McPhail et al&lt;sup&gt;70&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>QI</td>
<td>Inpatient</td>
<td>Missed follow-up appointment rate (within 90 d of discharge) was lower (20%) in the intervention (appointment made or listed in discharge summary, reminder phone call) compared with the partial intervention (45%; reminder placed in discharge summary) and no intervention (73%) groups (95% CI 0.006).</td>
<td>Weak</td>
</tr>
<tr>
<td>McPherson et al&lt;sup&gt;11&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Prospective cohort study</td>
<td>Inpatient</td>
<td>Twenty-eight percent missed follow-up appointments (no follow-up within 150% of defined time interval noted by discharging provider; most requested within 5 wk). Missed appointments were predicted by number of appointments (OR 6.3, 95% CI 2.5–15.2, <em>P</em> &lt; .001).</td>
<td>Weak</td>
</tr>
<tr>
<td>Nelson et al&lt;sup&gt;45&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>RCT</td>
<td>ED</td>
<td>Appropriate use of follow-up (keeping appointments, using primary care clinic instead of the ED for nonurgent care, using the telephone instead of unscheduled visits; assessed 8 d after discharge) was higher in the intervention (call to parent to explain diagnosis and treatment, reinforce follow-up instructions, provide support) compared with the control (usual care) group (80% vs 80%; <em>P</em> &lt; .05). More missed appointments in the control compared with the intervention group (51% vs 15%; <em>P</em> .05).</td>
<td>Moderate</td>
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<tr>
<td>Patel et al&lt;sup&gt;72&lt;/sup&gt;</td>
<td>Return precautions</td>
<td>Clinical controlled trial</td>
<td>ED</td>
<td>Mean recall of 7 warning signs (assessed 24–48 h after discharge) was higher in the intervention (written discharge instructions reinforced verbally in preferred language) compared with the historical control (4.3 [95% CI 4.1–4.5] vs 3.3 [95% CI 3.1–3.5]).</td>
<td>Weak</td>
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<tr>
<td>Pockett and Thompson&lt;sup&gt;58&lt;/sup&gt;</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Twenty percent did not properly adhere to prescription filling instructions (filling prescription if culture results were positive and not filling prescription if culture results were negative; assessed within 7 d of discharge). Nonadherence was significantly predicted by older child age.</td>
<td>Moderate</td>
</tr>
<tr>
<td>Polacek et al&lt;sup&gt;73&lt;/sup&gt;</td>
<td>Follow-up appointments</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Fifty-nine percent did not make or keep follow-up appointments within 2 wk of discharge. Common reasons for missing appointments were work or school conflicts, transportation problems, forgot, and returned to ED instead. Medical importance of follow-up and time to visit were significantly related to adherence in multivariable analysis (<em>P</em> &lt; .05).</td>
<td>Weak</td>
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<tr>
<td>Rice et al&lt;sup&gt;51&lt;/sup&gt;</td>
<td>Follow-up appointments, medications</td>
<td>RCT</td>
<td>Inpatient</td>
<td>Sixty-two percent missed follow-up appointments 7–10 d after discharge; there was no difference in appointment attendance in the intervention (individualized, family-based asthma education sessions) compared with the control (usual care). Controller medicine use (OR 2.4, 95% CI 1.3–4.2, <em>P</em> &lt; .01); spacer use (OR 2.9, 95% CI 1.1–7.4, <em>P</em> = .03), and having an asthma action plan at follow-up (OR 2.0, 95% CI 1.3–3.0, <em>P</em> &lt; .01) were more likely in intervention group.</td>
<td>Moderate</td>
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<tr>
<td>Rosman et al&lt;sup&gt;74&lt;/sup&gt;</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Thirty-two percent did not fill ≥1 prescription within 3 d of discharge (86% of these did not fill any prescriptions). There were no independent predictors of adherence.</td>
<td>Weak</td>
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<tr>
<td>Samuels-Kalogeropoulos et al&lt;sup&gt;15&lt;/sup&gt;</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Thirty-two percent made a medication dosing error at discharge. Dosing errors were more likely in Spanish-speaking compared with English-speaking parents (54% vs 25%; OR 3.7, 95% CI 1.6–8.1). This difference remained after adjusting for income and health literacy (aOR 4.7, 95% CI 1.5–14.9).</td>
<td>Weak</td>
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### TABLE 1 Continued

<table>
<thead>
<tr>
<th>Citation</th>
<th>Domain(s)</th>
<th>Study Design</th>
<th>Setting</th>
<th>Key Findings</th>
<th>Quality</th>
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<tbody>
<tr>
<td>Scarfone et al77</td>
<td>Follow-up appointments</td>
<td>Prospect cohort study</td>
<td>ED</td>
<td>Fifty-one percent of parents missed follow-up visits within the scheduled time frame (most within 48 h). Missed revisits were because the parent believed their child was not severely ill; the ED physician recognized the parent would not be able to recognize clinical deterioration, the parent was &lt;21 y old, no laboratory tests were performed, or the parent did not own a car</td>
<td>Weak</td>
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<tr>
<td>Smith et al47</td>
<td>Follow-up appointments</td>
<td>RCT</td>
<td>ED</td>
<td>The rate of missed asthma planning visits within 15 d of discharge was lower in the intervention (asthma coaching during ED visit and discussion of importance of follow-up as well as monetary incentive) compared with the control (usual care) group (64% vs 81%; P &lt; .0001). Intervention group status was associated with increased rate of follow-up visits (aOR 2.4, 95% CI 1.6–3.5, P &lt; .0001)</td>
<td>Moderate</td>
</tr>
<tr>
<td>Smith et al46</td>
<td>Follow-up appointments</td>
<td>RCT</td>
<td>ED</td>
<td>There was no significant difference in rates of missed asthma planning visits within 2 wk of discharge in the intervention (telephone asthma coaching after discharge to discuss importance of follow-up and barriers as well as monetary incentive) compared with control (usual care) group (78% vs 76%; P &gt; .05)</td>
<td>Moderate</td>
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<tr>
<td>Soliday and Hoekse78</td>
<td>General, follow-up appointments, medications</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Thirteen percent did not follow home care procedures. Forty-seven percent missed follow-up appointments. Twenty-one percent did not adhere to prescription medication instructions. Twenty-seven percent were nonadherent to nonprescription medication instructions (adherence assessed ∼10 d after discharge). Health beliefs (barriers, severity, susceptibility) and child age predicted postdischarge adherence</td>
<td>Weak</td>
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<tr>
<td>Staveski et al78</td>
<td>General, return precautions</td>
<td>Controlled clinical trial</td>
<td>Inpatient</td>
<td>Parent test scores (assessed within 48 h of discharge) were higher after implementation of a nursing discharge training program (3.7, SD 0.9) compared with before (1.8, SD 1.4, P &lt; .005). Scores were higher postintervention for all questions including when to seek medical care (97% vs 50%) and recognizing signs of infection (62%)</td>
<td>Weak</td>
</tr>
<tr>
<td>Stevens et al80</td>
<td>Return precautions</td>
<td>Prospective cohort study</td>
<td>ED</td>
<td>Seventy percent of parents whose children developed postconcussive symptoms did not recognize these as postconcussive symptoms 2–5 d after discharge.</td>
<td>Weak</td>
</tr>
<tr>
<td>Twagirumukiza et al80</td>
<td>Medications</td>
<td>Prospective cohort study</td>
<td>Inpatient</td>
<td>Postdischarge medication adherence (assessed 4 d after outpatient treatment) varied on the basis of measure used. Nonadherence was 0% for self-report, 0% for pill count method, and varied for electronic pill box monitoring (range: 17% [&gt;70% of doses taken] to 59% [&gt;80% of doses within 2 h around time dose is due])</td>
<td>Moderate</td>
</tr>
<tr>
<td>Voiro et al81</td>
<td>Medications</td>
<td>RCT</td>
<td>Inpatient</td>
<td>Fewer families failed to pick up medications within 24 h in the intervention (pharmacy, insurance status, and prescriptions verified, assistance in procurement of medications, caregivers educated and given written instructions and medication schedule) compared with the control (standard care: assistance when requested only) group (16% vs 31%; P = .03). Residence in California, number of medications, insurance type, and prescription for compounded medication (but not intervention status) predicted ability to obtain medications in adjusted analysis. Report of giving correct dose (91% intervention vs 94% control; P &gt; .05) and of correct frequency (89% intervention vs 94% control; P &gt; .05) of all medications did not significantly differ by intervention status</td>
<td>Weak</td>
</tr>
<tr>
<td>Waisman et al82</td>
<td>Diagnosis, medications</td>
<td>Cross-sectional study</td>
<td>ED</td>
<td>At discharge, 75% of parents fully understood the diagnosis (nature of problem, etiology, and diagnosis). Eighty-five percent of parents fully understood the medication instructions (indication, frequency, and duration). There were no significant predictors of knowledge of instructions. Parents believed that use of medical terminology (25%), anxiety and fatigue (29%), and no time for questions (17%) contributed to poor understanding</td>
<td>Weak</td>
</tr>
<tr>
<td>Waisman et al82</td>
<td>Diagnosis, medications</td>
<td>Controlled clinical trial</td>
<td>ED</td>
<td>At discharge, there was no difference in understanding of diagnosis (nature of problem, etiology, and diagnosis) in the intervention (handouts containing standardized, disease-specific discharge instructions) compared with the historical control (usual care) group (73% vs 72%; P &gt; .05). More intervention group parents could state medication instructions (indication, frequency, and duration of treatment) (82% vs 82%; P = .03)</td>
<td>Weak</td>
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<tr>
<td>Citation</td>
<td>Domain(s)</td>
<td>Study Design</td>
<td>Setting</td>
<td>Key Findings</td>
<td>Quality</td>
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<tr>
<td>Wang et al</td>
<td>Medications,</td>
<td>Prospective</td>
<td>ED</td>
<td>Twenty-three percent did not pick up medications within 2 d of discharge.</td>
<td>Weak</td>
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<tr>
<td></td>
<td>follow-up</td>
<td>cohort study</td>
<td></td>
<td>Medication nonadherence was predicted by public or no insurance. Twenty-six</td>
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<td></td>
<td>appointments</td>
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<td>percent did not attend follow-up appointments. Public or no insurance and</td>
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<td>low-acuity diagnoses predicted missed appointments</td>
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<tr>
<td>Wang et al</td>
<td>Medications,</td>
<td>Prospective</td>
<td>ED</td>
<td>Thirty-seven percent did not pick up prescribed medications. Public or no</td>
<td>Weak</td>
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<td></td>
<td>follow-up</td>
<td>cohort study</td>
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<td>insurance predicted medication nonadherence. Forty percent did not attend</td>
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<td></td>
<td>appointments</td>
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<td>follow-up appointments. Caregivers with public or no insurance, low acuity</td>
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<tr>
<td>Warren and</td>
<td>Return</td>
<td>Controlled</td>
<td>ED</td>
<td>There was no difference in the mean number of recalled return precautions</td>
<td>Weak</td>
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<tr>
<td>Kisssoon</td>
<td>precautions</td>
<td>clinical trial</td>
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<td>48 h after discharge in the intervention (written and verbal instructions)</td>
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<tr>
<td>Wiens et al</td>
<td>Follow-up</td>
<td>Controlled</td>
<td>Inpatient</td>
<td>Inpatient Subjects receiving the intervention (postdischarge referral</td>
<td>Weak</td>
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<tr>
<td></td>
<td>appointments</td>
<td>clinical trial</td>
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<td>organized by nurse, discharge kit including counseling) were more likely to</td>
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<td>complete ≥1 follow-up appointment (88%) on day 2, 7, or 14 after discharge</td>
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<td>compared with the control (verbal instructions only) group (4.0 vs 3.9).</td>
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<tr>
<td>Williams et</td>
<td>Follow-up</td>
<td>Controlled</td>
<td>ED</td>
<td>Fewer subjects in the intervention (modified instructions with visual and</td>
<td>Weak</td>
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<tr>
<td></td>
<td>appointments</td>
<td>clinical trial</td>
<td></td>
<td>numerical representations of clinical asthma score and ED provider explains</td>
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<tr>
<td>Wolff et</td>
<td>Follow-up</td>
<td>RCT</td>
<td>ED</td>
<td>Adolescent patients receiving the intervention (4 text message reminders)</td>
<td>Strong</td>
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<td></td>
<td>appointments</td>
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<td>were more likely to attend follow-up appointments within 3 d of discharge</td>
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<td></td>
<td>(44%) compared with controls (15%, RR 2.9, 95% CI 1.3–6.1).</td>
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<tr>
<td>Yang et al</td>
<td>General</td>
<td>Controlled</td>
<td>Inpatient</td>
<td>Maternal general knowledge scores of home care regimen at 1 wk and 1 mo</td>
<td>Weak</td>
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<td></td>
<td></td>
<td>clinical trial</td>
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<td>postdischarge were significantly higher than pretest scores in the intervention</td>
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<td>(parent educated and participated in care of infant during hospitalization,</td>
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<td>home visits, phone calls plus usual care) compared with the control (usual</td>
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<td>care group) (4-point score increase versus unchanged score; (P &lt; .001))</td>
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<tr>
<td>Yin et al</td>
<td>Medications</td>
<td>RCT</td>
<td>ED</td>
<td>Medication dose knowledge errors were less likely in the intervention (enhanced</td>
<td>Moderate</td>
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<td>counseling with dosing demonstrating how and teach-back facilitated by plain</td>
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<td>language, pictogram-based instruction sheet) compared with the control (</td>
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<td>standard counseling) group (0% vs 15%, (P = .007)). Adherence errors were</td>
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<td>less likely in the intervention compared with the control group (8% vs 38%,</td>
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<td>(P = .002). Dosing errors were less likely in the intervention compared</td>
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<td>with the control group for prescribed (5% vs 48%, (P &lt; .001)) and as-needed</td>
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<td>(16% vs 40%, (P = .003)) medications. Assessments were performed 3–5 d</td>
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<td>after discharge for as-needed medicines and within 1 d of projected end date</td>
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<td>(up to 2 wk after discharge) for daily dose medicines</td>
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<td>Yin et al</td>
<td>Medications</td>
<td>Cross-</td>
<td>ED</td>
<td>Within 1 d of projected end date of medication course (up to 2 wk after</td>
<td>Weak</td>
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<td></td>
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<td>sectional</td>
<td></td>
<td>discharge), 32% of patients had errors in knowledge of medication dose.</td>
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<td>study</td>
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<td>Seventeen percent used a nonstandard instrument (kitchen spoon). Forty-</td>
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<td>one percent made a dosing error in the prescribed dose. Parents who used</td>
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<td>teaspoon or tablespoon units (compared with milliliters) were more likely to</td>
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<td>make errors in prescribed dose. Associations were greatest in caregivers who</td>
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<td>were Spanish-speaking and had low health literacy. Using a nonstandardized</td>
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<td>instrument led to more errors and was a partial mediator in the relationship</td>
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<td>between use of tablespoon or teaspoon units and making measurement errors</td>
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<tr>
<td>Yin et al</td>
<td>Medications</td>
<td>Cross-</td>
<td>ED</td>
<td>Within 1 d of projected end date of medication course (up to 2 wk after</td>
<td>Weak</td>
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<td></td>
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<td>sectional</td>
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<td>discharge), 41% of parents made a dosing error. Thirty-three percent of</td>
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<td>study</td>
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<td>parents received counseling with advanced strategies (teach-back, show-</td>
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<td>back, pictures or drawings, demonstration). Seventy-five percent of parents</td>
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<td>received a dosing instrument. Parents who received a dosing instrument and</td>
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<td>reported use of advanced counseling strategies were less likely to make a</td>
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<td>dosing error (aOR 0.3, 95% CI 0.1–0.7, (P = .004)). In adjusted analyses,</td>
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<td>provision of a dosing instrument or use of an advanced counseling strategy</td>
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<td>alone were not associated with error rates</td>
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to reinforce instructions\textsuperscript{72} or when standardized verbal and written discharge instructions were used.\textsuperscript{49}

**Diagnosis (3 Studies)**

Researchers for 3 studies assessed parental knowledge of their child’s diagnosis.\textsuperscript{61,82,83} Between 70\% and 79\% of parents could state their child’s diagnosis.\textsuperscript{61,82,83} Presence of multiple diagnoses led to increased error rates.\textsuperscript{61}

**Activity Restrictions (2 Studies)**

Researchers for 2 studies examined parental execution of instructions related to activity restrictions after concussion or mild traumatic brain injury.\textsuperscript{52,63} Between 20\% and 39\% of parents were nonadherent to activity-restriction instructions.\textsuperscript{52,63} Other restriction types (bathing, diet, school return) or restrictions related to other diagnoses were not examined in any of the studies reviewed.

**Equipment (1 Study)**

Researchers for 1 inpatient study examined parental knowledge of equipment instructions.\textsuperscript{64} Knowledge scores related to various types of equipment ranged between 50\% and 100\% depending on equipment type. Knowledge was highest for questions related to Broviac care and apnea monitoring and lowest for questions related to gastrostomy tube feeding (basic treatment knowledge) and total parenteral nutrition (operation and maintenance).\textsuperscript{64} Scores were lower when the child used multiple equipment types.\textsuperscript{64}

**General (7 Studies)**

Researchers for 7 studies examined parental knowledge of discharge instructions without a focus on a particular domain of care.\textsuperscript{33,48,54,64,78,79,89} There was variability across studies in how parental knowledge was scored and reported, including percent of parents with total comprehension of all instructions and study-specific knowledge scales (see Table 1).

**DISCUSSION**

In this systematic review, we found that many parents had difficulty managing the instructions they received when their child was discharged from the inpatient setting or ED. In particular, many families made medication dosing errors, had poor medication adherence, and had poor attendance at follow-up appointments. Several domains of care were understudied.

We highlighted in our review that medication dosing errors are common. Although adults often have difficulty managing their own medication instructions,\textsuperscript{3,11,92} we found that parents had particular difficulty dosing liquid medications, with one-third to almost half of parents making dosing errors.\textsuperscript{50,75,90,91} Notably, because researchers for all of these studies used observed dosing assessments of parents whose children were discharged from the ED, future researchers should examine whether dosing error rates are similar after inpatient discharge.

Medication adherence errors were also prevalent. Almost one-third of low-income families failed to pick up their child’s prescriptions.\textsuperscript{37,74} Medication adherence errors rates by self-report were as high as 40\% in a low-income, low-health-literacy population.\textsuperscript{50} Actual adherence may be even worse because self-reported adherence often overestimates actual adherence; in 1 study, self-reported nonadherence was 0\%, whereas nonadherence rates based on electronic pill box monitoring were as high as 60\%.\textsuperscript{39}
Although medication management was addressed in several studies, medication side effects were understudied. Side effects were poorly understood in the 1 study in which they were examined, with half of the parents making errors; this is consistent with the difficulties that adults have in understanding side effects of their own medications. Patients given counseling on medication side effects have been found to have lower rates of adverse drug events; researchers for future studies should examine parental understanding of medication side effects and focus on improving the way providers counsel families in this area.

Parents also frequently made errors related to managing follow-up appointment instructions. Parents who did not understand appointment instructions were more likely to miss appointments and authors of many studies found that more than half of parents missed follow-up appointments. Our findings were consistent with studies in which the difficulty adult patients have managing their own appointment-related instructions was documented. In this review, we highlight important gaps in the literature related to parental management of discharge instructions. Only 2 inpatient studies were conducted by researchers who examined management of instructions related to equipment, finding that understanding varied depending on the type of equipment and type of knowledge being assessed. Researchers for future studies should explore this topic because physicians typically do not provide substantial counseling about restrictions, putting children at risk for adverse outcomes after discharge.

Only 1 study, published in 1987, was conducted by researchers who examined management of instructions related to equipment, finding that understanding varied depending on the type of equipment and type of knowledge being assessed. Researchers for future studies should explore this topic because 10% of pediatric admissions in the United States are for children with complex chronic conditions, many of whom are equipment-dependent.

Although parents made management errors across multiple domains of care, several common risk factors were identified. Limited English proficiency, public or no insurance, and minority race/ethnicity were associated with increased error rates. This is not surprising because these high-risk groups are disproportionately affected by low health literacy, and children whose parents have low health literacy have worse health outcomes. Children with low health literacy are at an increased risk of misunderstanding physician instructions. Despite this, health literacy was assessed in only 5 ED studies and no inpatient studies in our review. Because nearly 1 in 3 US parents have low health literacy, future work is needed to examine the intersection between parental health literacy and knowledge and execution of discharge instructions.

Additional factors that led to errors in knowledge and execution of discharge instructions included when children were older and had a diagnosis of lower acuity. Researchers should explore why these risk factors are associated with errors, whether it is because of poor provider counseling, parent-related factors, or both. Finally, discharge plans that were complex (e.g., multiple medications, appointments, equipment types) were also associated with higher error rates, suggesting that more in-depth counseling and use of health literacy-informed counseling strategies might be especially important in these cases.

Furthermore, the type and modality of counseling used can affect knowledge and execution of discharge instructions; the use of multimodal counseling can decrease error rates. For example, giving written and verbal instructions, as opposed to verbal instructions alone, led to decreased errors. One of the most effective interventions used techniques such as demonstrating measurement of liquid medications and teach-back and show-back of the dose, facilitated by health literacy-informed, pictogram-based instruction sheets; this intervention led to decreased dosing (42% absolute risk reduction) and adherence (29% absolute risk reduction) errors. Use of teach-back can be a key strategy in helping families navigate complicated instructions and to decrease error rates. This may be especially important as errors in knowledge have been shown to lead to errors in execution of instructions and families may not be aware when they do not understand instructions. It would be beneficial to assess parental knowledge of instructions at the time of discharge to prevent errors.
discharge and counsel families by using health literacy-informed counseling strategies, such as teach-back, to prevent adverse outcomes at home. Other counseling strategies may also improve management of discharge instructions. Providing tailored education sessions and simply spending more time with families led to improved comprehension of instructions. Video discharge instructions also led to higher knowledge levels compared with standard instruction methods.

Interventions with a focus on standardizing discharge instructions (eg, use of disease-specific written discharge instructions, presenting verbal counseling in a consistent manner) led to improvements in management. Because standardized instructions result in improved provider counseling, are preferred by parents, and lead to decreased errors, the use of such instructions should be strongly considered. Other interventions that helped families navigate the process of executing instructions also led to decreased error rates; this included scheduling appointments for patients and assisting families in obtaining medications. Finally, making follow-up reminder phone calls were also effective in reducing errors.

This review has limitations. The possible risk of bias is high given that more than half of the studies included had a weak overall quality rating, mostly because of researchers using convenience sampling. This sampling method may have led to an underestimation of error rates because of exclusion of weekend and evening discharges. Our review also included several studies that were cross-sectional in nature, quality improvement, and not blinded (also not given strong Quality Assessment Tool for Quantitative Studies ratings). Nonetheless, evidence from these studies is still sufficiently strong to draw the conclusion that parents have difficulty managing discharge instructions and provide the impetus for future randomized controlled trials. In addition, most studies restricted enrollment on the basis of language (ie, only including English- or Spanish-speaking caregivers), which limits generalizability. We also examined multiple outcomes. Not only were these outcomes measured in several different ways, but they were assessed at different times as well, and therefore a meta-analysis could not be performed. No clear pattern existed, however, with regard to how or when assessments were performed and error rates. We specifically focused on caregiver knowledge and execution of discharge instructions from the inpatient and ED settings. Other settings, such as the NICU and newborn nursery, and psychiatric hospitals, are also associated with misunderstanding of instructions and readmissions but deal with distinct populations and types of instructions and therefore deserve their own review. Lastly, although we screened several thousand records, we did not include conference abstracts or other elements of gray literature, so publication bias may be an issue.

CONCLUSIONS

Many parents have difficulty managing instructions they receive when their children are discharged from the inpatient and ED settings. In addition, several domains of care (such as restrictions [diet, bathing, activity, and school return], return precautions, equipment, and medication side effects) were understudied and should be the focus of future studies. Researchers conducting future reviews should also address management of instructions from other settings, including the newborn nursery, NICU, and outpatient setting. Researchers should also focus on the design interventions that improve parental management of discharge instructions.

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ABBREVIATION

ED: emergency department
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The reference list continues with other cited works, but the provided text does not include all the references listed in the image.
and primary care follow-up rates. 


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