**Marquette University**

**e-Publications@Marquette**

***Department of Computer Science Faculty Research and Publications/College of Arts and Sciences***

***This paper is NOT THE PUBLISHED VERSION*.**

Access the published version via the link in the citation below.

*Western Journal of Nursing Research*, (May 28, 2021). [DOI](http://doi.org/10.1177/01939459211018829). This article is © SAGE Publications and permission has been granted for this version to appear in [e-Publications@Marquette](http://epublications.marquette.edu/). SAGE Publications does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from SAGE Publications.

One Size Does Not Fit All: Discharge Teaching and Child Challenging Behaviors

Norah L. Johnson

College of Nursing, Marquette University, Milwaukee, WI, USA

Stacee Lerret

Medical College of Wisconsin, Milwaukee, WI, USA

Michele Polfuss

Children’s Wisconsin, Milwaukee, WI, USA

College of Nursing, University of Wisconsin Milwaukee, Milwaukee, WI, USA

Karen Gralton

Children’s Wisconsin, Milwaukee, WI

Cori Gibson

Children’s Wisconsin, Milwaukee, WI, USA

Sheikh I. Ahamed

Department of Computer Science, Marquette University, Milwaukee, WI, USA

Adib Riddhiman

Department of Computer Science, Marquette University, Milwaukee, WI, USA

Rosemary White-Traut

Children’s Wisconsin, Milwaukee, WI, USA

Roger L. Brown

School of Nursing, University of Wisconsin, Madison, WI, USA

Kathleen J. Sawin

Children’s Wisconsin, Milwaukee, WI, USA

College of Nursing, University of Wisconsin Milwaukee, Milwaukee, WI, USA

# Abstract

This study compares quality of discharge teaching and care coordination for parents of children with challenging behaviors participating in a nursing implementation project, which used an interactive iPad application, to usual discharge care. Unlike parents in the larger quasi-experimental longitudinal project, parents of children with challenging behaviors receiving the discharge teaching application (n = 14) reported lower mean scores on the quality of discharge teaching scale–delivery subscale (*M* = 8.2, *SD* = 3.1) than parents receiving usual care (n = 11) (*M* = 9.6, *SD* = 4.7) and lower scores on the Care Transition Measure (*M* = 2.44, *SD* = 1.09) than parents receiving usual care (*M* = 3.02, *SD* = 0.37), with moderate to large effects (0.554–0.775). The discharge teaching approach was less effective with this subset, suggesting other approaches might be considered for this group of parents. Further study with a larger sample specific to parents of children with challenging behaviors is needed to assess their unique needs and to optimize their discharge experience.

# Keywords

Child challenging behaviors, Discharge teaching, Parent engagement

The transition from hospital to home can be stressful for families of hospitalized children who demonstrate challenging behaviors sometimes referred to as behaviors of frustration (e.g., self-injury, hitting, repetitive behaviors, and running away) and evoke their parents’ fear and anxiety (Johnson et al., 2014; Johnson & Rodriguez, 2013). Children with challenging behaviors commonly experience stress and anxiety when hospitalized due to uncertainty about when they will be ready to go home and from novel stimuli such as hypersensitivity to light and sound (Straus et al., 2019). This combination of the challenging behaviors and parental fear and anxiety may make the child’s treatment difficult to manage in terms of cooperating with assessments and procedures. Furthermore, it can interfere with the parent’s ability to listen, comprehend, internalize, and personalize the discharge instructions. As a result, parents may not be prepared with the knowledge and confidence they need to help their child recover at home (Johnson & Rodriguez, 2013).

Children with challenging behaviors may have an autism spectrum disorder (ASD) diagnosis and/or other conditions such as attention deficit hyperactivity disorder, language disorder, bipolar disorder, depression, and anxiety disorder (Avni et al., 2018; Levy et al., 2010). The prevalence of challenging behaviors is difficult to estimate as they are generally reported as part of disease conditions (e.g., ASD) and not directly measured. A national survey of children’s health, involving 78,042 households in the United States between 2005 and 2011, indicated that 4.6% of children between 3 and 17 years old had a history of disruptive behavior disorders, anxiety (4.7%), depression (3.9%), and ASD (1.1%) (Perou et al., 2013). Children admitted for medical or surgical issues can have co-occurring challenging behaviors that are not the reason for the hospitalization. To date, no studies have provided evidence about the discharge experience of children with challenging behaviors from a pediatric hospital (Straus et al., 2019).

# Discharge Preparation

Discharge is a complex process. Essentials of discharge preparation have been identified of which family education is a key component (Berry et al., 2014). While there are many approaches to discharge teaching (Bajorek & McElroy, 2020), they all include some aspects of the IDEAL discharge model (Agency for Healthcare Research and Quality [AHRQ], 2013). IDEAL has five essential components, each of which involves interaction with parents to prepare children for discharge: (1) include the patient and family, (2) discuss key areas to prevent problems at home, (3) educate in plain language, (4) assess understanding using teach-back (AHRQ, 2017), and (5) listen to and honor goals, preferences, observations, and concerns [IDEAL (AHRQ, 2013)].

Family members of children with challenging behaviors value individualized attention to their child’s needs by an engaged health care provider (Koski et al., 2016). Parents need to feel both prepared and capable to implement care once they return home, as well as cared for by those providing the teaching (Mitchell et al., 2018). Family engagement is particularly important for families of children with diagnoses that include challenging behaviors as parents tend to know the particular triggers for their child’s behavior (Straus et al., 2019). Systems have been developed across the health care continuum to increase family engagement by including families as part of the health care team, forming collaborative partnerships, making decisions, and fostering communication between providers and family members (Cene et al., 2016).

When providers use empathetic language, family members are more trusting of the discharge teaching and are encouraged to follow through on implementation of the teaching (Mitchell et al., 2018). Additionally, nurses skilled in engaging parents can better prepare them to be able to recall and draw upon discharge teaching when needed at home (Berger et al., 2014). Ideally, hospital discharge teaching begins on admission and continues throughout the hospitalization and is reviewed on the day of discharge, but since it is often hard to predict the day of discharge, the timing of the process varies (Berry et al., 2014; Sullivan et al., 2015). Quality delivery of discharge teaching by the nurse to a parent engaged in the process has been shown to best prepare parents to cope and care for their children after discharge (Weiss et al., 2008, 2017).

Our team of researchers has a progressive program of research focusing on hospital discharge. As part of a larger project, we developed and implemented the engaging parents in education for discharge (*e*PED) iPad application (app), a theory-based day-of-discharge teaching developed and implemented at a Midwest pediatric hospital to improve discharge teaching effectiveness and parent outcomes (Lerret et al., 2020; Johnson, Lerret, et al., 2020).

In an evaluation of the effectiveness of the *e*PED app, parents receiving the day-of-discharge teaching guided by the app as a supplement to their usual discharge teaching had higher quality of discharge teaching scores than parents receiving only usual discharge teaching (Lerret et al., 2020). However, in an evaluation of the *e*PED implementation using the Reach, Adoption, Evaluation, Maintenance (RE-AIM) framework (Glasgow et al., 2006), there was not full reach or adoption of the *e*PED app, meaning that some of the nurses did not use the app to guide their day-of-discharge teaching or started using the app and stopped using it before completing the discharge (Johnson, Lerret, et al., 2020). Based on informal interviews with nurse participants, nurses perceived that some parents reported being in a hurry to get home and were dealing with child behaviors that may have interfered with their attention and patience with the *e*PED implementation (Johnson, Lerret, et al., 2020). These results stimulated our interest in evaluating the use of the *e*PED app in this subset of parents from the original study who reported challenging child behaviors and who have the potential for greater difficulty at times of transition.

# Purpose

The purpose of this secondary analysis was to compare parent perception of the quality of discharge teaching and care coordination for parents of children with challenging behaviors who received teaching from nurses using the *e*PED app compared to parents who received usual discharge teaching.

# Methods

## Design

This secondary analysis of a larger two-group pre/post-test quasi-experimental two-unit implementation project was designed to test the effectiveness of the iPad-application-guided discharge (Lerret et al., 2020) in a specific subset of parents of children with challenging behaviors. Outcomes evaluated were the quality of discharge teaching, care coordination, and post-discharge outcomes. With the implementation group, a discharge nurse used the *e*PED app to guide the discharge teaching, which supplemented usual discharge teaching that included verbal teaching interactions with the discharging nurse and written discharge instructions. For the comparison group parents, the discharge nurse provided “usual care” discharge teaching.

## Sample and Setting

The study took place on two units of a pediatric hospital in the Midwestern United States. The first unit was a surgical unit that served as the *e*PED implementation unit and the second unit was a medical unit that served as the usual discharge care unit. All staff nurses on both units completed the training on the *e*PED app implementation study. Of the 211 parents of children with acute, chronic, and complex health conditions in the larger study, there were 14 who answered “yes” to the question “Does your child exhibit one or more of the following behaviors of frustration: Self-injury or injury to others or self-calming such as rocking?” from the implementation unit, and 11 of the 184 parents who received usual discharge care on the usual care unit.

## ePED Discharge Teaching Application

The *e*PED app was designed to promote parent engagement on the day of discharge by providing scripting for nurse interactions, with parents across five domains of discharge material across five screens of the app: (1) signs and symptoms, (2) medications, (3) appointments and results, (4) recovery, and (5) thinking forward to family adjustment (Lerret et al., 2020). The *e*PED app is based on three frameworks: (1) the individual and family self-management theory (IFSMT) (Ryan & Sawin, 2009), (2) Tanner’s model of clinical judgment (Tanner, 2006), and (3) teach-back method (AHRQ, 2017). First, the app guides the nurse to support the process of self-management by focusing on the risks and complexities as well as the strengths of the family in managing the child’s condition as they transition between hospital and home (Sawin et al., 2017). Second, using Tanner’s model of clinical judgment (Tanner, 2006), nurses formulate responses to parent feedback from the *e*PED app questions using their expertise and clinical judgment. Third, the teach-back method (AHRQ, 2017) is incorporated in the *e*PED app as questions on the app require the parents to interact with nurses so the nurse knows the parents understand how to support ongoing recovery in the home environment.

Together, the nurse and parent/caregiver think ahead about what life will be like once the parent/caregiver and child return home by eliciting specific plans, potential concerns, knowledge gaps, and additional teaching needs (Johnson, Lerret, et al., 2020; Lerret et al., 2020). For example, the first screen of the *e*PED app covers signs and symptoms. The first question is: “Let’s talk about things to watch for in the first few days or weeks after your child is home. Tell me how you would know if your child is not doing well? What will you watch for? What will you do to keep track of these things?” For the fifth screen on “Thinking forward to family adjustment” sample questions included the following: “In taking your child home from the hospital, what adjustments will you make? Have you thought about changes you and your family will have to make for your other children, your job, childcare and/or other family members? There will be things that other caregivers will need to learn. How will they learn them and when? Who can you count on to give you emotional support if you are worried or stressed?” A full description of the development of the initial content (Sawin et al., 2017), subsequent content reduction, *e*PED app development, and implementation are published elsewhere (Johnson, Lerret, et al., 2020; Lerret et al., 2020).

## Measures

### Quality of Discharge Teaching

The 12-item quality of discharge teaching scale–delivery subscale (QDTS-D) of the QDTS was used to measure the parent’s perspective on the quality of the delivery of discharge teaching throughout the hospitalization (Weiss et al., 2008). This subscale reflects the skill of the nurses as educators in presenting discharge teaching. The items include: listening to and answering specific questions and concerns, being sensitive and understanding of personal beliefs and values, using health-literate terminology, teaching at times that were good for parents and family members, providing consistent information, promoting confidence in ability to care for the child and in knowing what to do in an emergency, and decreasing parent anxiety about the transition home. The QDTS-D responses are on a Likert scale ranging from “not at all” (0) to “always” (10). The reliability of the tool is high for samples of parents of hospitalized children with Cronbach’s alpha at 0.88 (Lerret et al., 2014; Weiss et al., 2008). The QDTS-D scale score is reported as the mean of the item scores, with higher scores reflecting parent’s perception of receiving better quality of discharge teaching.

### Care Coordination

The Care Transition Measure (CTM) was used to measure care coordination (Coleman et al., 2002). The CTM-15 is a 15-item measure that has four key domains: (1) transfer of information, (2) preparation of patient/caregiver, (3) self-management support, and (4) empowerment to address preferences. The reliability of the tool is high in both the adult and pediatric populations with a Cronbach’s alpha of 0.92–0.93 (Coleman et al., 2005; Lerret & Weiss, 2011; Lerret et al., 2015). The CTM responses use a 4-point Likert scale with responses ranging from “strongly disagree to strongly agree.” The CTM total score represents the overall parent perceived quality of the care transition, with lower total scale scores reflecting poorer transition and higher scores reflecting a better transition (Coleman et al., 2002).

### Child and Family Characteristics

Child and family characteristics were collected by parent self-report to describe the sample. Characteristics included: parent’s age, gender, ethnicity, race, marital status, and employment, child age, sex, race, reason for hospitalization, psychiatric/ behavioral comorbidities, number of adults and children in the home, number of medications, and types of insurance.

## Procedures

Institutional Review Board (IRB) approval was obtained for the larger implementation study. A waiver of documentation of consent was approved for this evaluation of unit-wide implementation of the enhanced approach to discharge teaching with all nurses trained in the use of the discharge teaching process using the *e*PED app. Parents received an information sheet explaining the study components and a verbal explanation by the bedside nurse on both the *e*PED app implementation and the usual care unit of the hospital.

The content development for the *e*PED iPad app, staff training, and the data collection took place between September 2018 and January 2019. Only the parents on the implementation unit received the discharge teaching guided by the *e*PED app. Standard teaching with written information sheets was completed on both units. Data collected on the day of discharge for all participants included the two-parent experience questionnaires (QDTS-D and CTM) and a questionnaire on child and family characteristics used to describe the sample; the questionnaire was completed by the parents on an iPad provided by the study. The discharging nurse handed the iPad to the parent to respond to the questionnaires immediately on completion of the discharge teaching. Parents on both units completed the questionnaires independently and closed the app prior to returning the iPad to the bedside nurse. Study data collected via the iPad was directly entered into a REDCap database.

## Data Analysis

In this analysis, we were interested in assessing possible treatment effects of discharge teaching using the *e*PED iPad app. Therefore, covariate balance was crucial for unconfounded descriptive or causal comparisons (Holmes & Olsen, 2010). However, lack of balance is common in studies with small sample sizes. Propensity scores were used to minimize the confounding of treatment effects with group differences (unbalance of covariates). The propensity score method involves calculating the conditional probability (propensity) of being in the implementation group (exposure to the *e*PED) given a set of covariates, weighting the data based on these propensity scores, and then analyzing the outcome using the weighted data. Even though small samples have larger error variances than large sample studies, usable results can be produced to control for covariate imbalance in comparison groups (Holmes & Olsen, 2010). To obtain propensity weights, we used generalized boosted modeling, an automated algorithm that uses covariates to predict treatment assignment (McCaffrey et al., 2004, 2013). The covariates in the models (listed in Table 3) included: parent age, child age, gender of parent, gender of child, number of medications, number of comorbid conditions, marital status, reasons for admission (medical or surgical). The covariates were analyzed to see how unbalanced the two groups were (n = 14 compared to n = 11). Unbalance would bias the estimated means and the effect size. Balancing the covariates gives a better idea of the effect size differences. First, we developed unweighted raw covariate means and proportions for all participants in both groups. A one-to-one effect size would be zero, showing that both groups would be the same and would not be a biasing factor. Unbalance was based on calculating effect size differences, with values greater than 0.20 indicating unbalance. Next, it is suggested that after covariate balancing if some covariates are still unbalanced, one may create a doubly robust weighting by including those unbalanced covariates in the regression model (Tsiatis & Davidian, 2007). Propensity weights are established for each participant and incorporated into a simple multiple regression model with group [implementation vs. usual car/comparison] and any further unbalanced covariates. All analyses were conducted using Stata version 16.1 (StataCorp., 2019).

# Results

The sample included 25 parents, with 56% (n = 14) who received the teaching guided by the iPad app and 44% (n = 11) who received usual care. Parent and child characteristics are presented in Table 1. Parents in both groups were primarily female, predominantly of white race and non-Latinx ethnicity, and half were married. Compared to the usual care group (parent/caregiver mean age 36 years, *SD* 8.8 years), the *e*PED group were younger (parent/caregiver mean age 32.5 years, *SD* 12.5 years), included fewer white and more African-American parents, were more likely to work full-time and have Medicaid insurance. In addition, their children were younger (mean age 6.8 years, *SD* 5.1) had more Autism diagnoses and language disorder diagnoses compared to usual care children (mean age 8.3 years, *SD* 4.7 years ) who had more anxiety and eating disorders, and took more medications.

**Table 1.** Sample Characteristics of Children with Behaviors of Frustration and Their Parent/Caregiver (n = 25).

|  |  |  |
| --- | --- | --- |
|  | ePED Implementation (n = 14) N (%) | Usual Care (n = 11) N (%) |
| Parenting/caregiver sex: |  |  |
| Female | 10 (71.4) | 9 (81.8) |
| Male | 4 (28.6) | 2 (18.2) |
| Parenting/caregiver role: |  |  |
| Mother | 10(71.4) | 8 (72.7) |
| Father | 3 (21.4) | 2 (18.2) |
| Grandmother | 0 (0) | 1 (9.1) |
| Grandfather | 1 (7.1) | 0 (0) |
| Parent ethnicity: |  |  |
| Hispanic/Latinx | 2 (14.3) | 1 (9.1) |
| Non-Hispanic/Latinx | 12 (85.7) | 10 (90.9) |
| Parent race: |  |  |
| White | 8(57.1) | 7 (70) |
| Black | 4 (28.6) | 2 (20) |
| Asian | 1 (7.1) | 0 (0) |
| Multiple | 1 (7.1) | 1 (10) |
| Missing | 0 (0) | 1 (10) |
| Marital status: |  |  |
| Married | 7 (50) | 7 (45.5) |
| Single | 5 (35.7) | 2 (18.2) |
| Divorced | 1 (7.1) | 2 (18.2) |
| Widowed | 1 (7.1) | 2 (18.2) |
| Child sex: |  |  |
| Female | 7 (50) | 5 (42.9) |
| Male | 7 (50) | 6 (57.1) |
| Child ethnicity: |  |  |
| Hispanic/Latinx | 1 (7.1) | 1 (9.1) |
| Non-Hispanic/Latinx | 13 (92.9) | 10 (90.9) |
| Reason for hospitalization: |  |  |
| Medical | 5 (35.7) | 8 (72.7) |
| Surgical | 9 (64.3) | 3 (27.7) |
| Number of medications: |  |  |
| 0 | 0 (0) | 1 (9.1) |
| 1–3 | 6 (42.9) | 2 (18.2) |
| 4–10 | 7 (50) | 8 (72.7) |
| >10 | 1 (7.1) | 0 (0) |
| ADHD: | 2 (14) | 3 (27.3) |
| Anxiety disorder | 0 (0) | 4 (36.4) |
| Autism | 4 (28.6) | 2 (18.2) |
| Bipolar disorder | 0 (0) | 1 (9.1) |
| Depression | 1 (7.1) | 3 (27.3) |
| Eating disorder | 1 (7.1) | 2 (18.2) |
| Language disorder | 3 (21.4) | 0 (0) |
| Sleep disorder | 1 (7.1) | 1 (9.1) |
| None of the disorders | 6 (42.9) | 4 (36.4) |
| Type of insurance: |  |  |
| Private | 4 (28.6) | 1 (9.1) |
| Medicaid | 9 (64.29) | 11 (100) |
| Military | 2 (14.3) | 0 (0) |
| Self-pay | 0 (0) | 0 (0) |
| Parent/caregiver employment: |  |  |
| No work | 4 (28.6) | 5 (45.5) |
| Full time | 7 (50) | 2 (18.2) |
| Part time | 3 (21.4) | 4 (36.4) |
| Adults in the home: |  |  |
| 1 | 3 (21.4) | 5 (45.5) |
| 2 | 11 (78.6) | 5 (45.5) |
| 3 | 0 (0) | 1 (9.1) |
| Children in the home: |  |  |
| 1 | 6 (42.9) | 3 (27.3) |
| 2 | 4 (28.6) | 3 (27.3) |
| 3 | 2 (14.3) | 4 (36.4) |
| 4 | 2 (14.3) | 0 (0) |
| 5 | 0 (0) | 1 (9.1) |

SD = standard deviation.

Table 2 presents the mean scores on the two outcome measures. Unadjusted means are reported as well as adjusted means after weighting for co-variates. Scale scores for parents in both groups were at the higher end of the QDTS-D (>8 out of 10) and near the center point of the CTM scale (2.4–3 on a 1–4 scale). Scores on both the QDTS-D and CTM were higher for usual care/comparison group parents than *e*PED parents.

**Table 2.** Comparison of the Parent Experience Outcomes for the ePED and the non-ePED Parent Groups.

|  |  |  |
| --- | --- | --- |
|  | *e*PED Group (n = 14) Mean (*SD*) (Min–Max) | Non-*e*PED Group (n = 11) Mean (*SD*) (Min–Max) |
| QDTS-D unadjusted | 8.2 (3.1) (0–10) | 9.6 (4.7) (8.75–10) |
| adjusted\* | 8.05 (1.04) | 9.74 (0.29) |
| CTM unadjusted | 2.44 (1.09) (1–4) | 3.02 (.37) (1–4) |
| adjusted\* | 2.46 (0.37) | 2.96 (0.12) |

Note: Quality of discharge teaching scale-delivery (QDTS-D), Care Transition Measure (CTM).

Adjusted\* = after adjustment for covariate weighting.

The generalized boosted model provided the mean and SD weighted adjustments for the covariates (refer to Table 3). In the weighted model, the child ages for the two groups are closer than in the unweighted model (73.14 months for those that received the app compared to 78.17 months for the usual care group). Two of the covariates: (1) reason for hospitalization (medical or surgical ) and (2) condition 6-eating disorder was still unbalanced (effect size >0.20) after weighting and were included in the doubly robust models.

**Table 3.** Unweighted and Weighted Covariates.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Unweighted Raw Covariates (Unbalanced) |  |  |  |  | Weighted Covariates (Balanced) |  |  |  |  |
| Continuous Covariates | Non-*e*PED Mean/ Proportion | Non-*e*PED Unit *SD* | *e*PED Unit Mean | *e*PED Unit  *SD* | Effect Size | Non-*e*PED Unit Mean | Non-*e*PED Unit *SD* | *e*PED Unit Mean | *e*PED Unit  *SD* | Effect Size |
| Family age: | 32.5 | 12.55 | 36.333 | 8.5 | −0.354 | 32.378 | 11.724 | 35.149 | 7.681 | −0.256 |
| Child age month: | 72.64 | 61.44 | 98.33 | 60.86 | −0.419 | 73.14 | 63.28 | 78.17 | 59.84 | −0.082 |
| Number of medications: | 1.643 | 0.633 | 1.667 | 0.651 | −0.038 | 1.71 | 0.65 | 1.766 | 0.564 | −0.09 |
| Comorbid sum: | 0.929 | 1.072 | 1.000 | 1.044 | −0.069 | 0.939 | 1.091 | 1.214 | 1.167 | −0.265 |
|  | Control Unit | Control | Treatment Unit | Treatment | Effect | Control Unit | Control | Treatment Unit | Treatment | Effect |
| Categorical Covariates | Proportion | Unit *SD* | Proportion | Unit *SD* | Size | Proportion | Unit *SD* | Proportion | Unit *SD* | Size |
| Family gender: female | 0.643 | 0.479 | 0.75 | 0.433 | −0.232 | 0.685 | 0.464 | 0.752 | 0.432 | −0.144 |
| Family gender: male | 0.357 | 0.479 | 0.25 | 0.433 | 0.232 | 0.315 | 0.464 | 0.248 | 0.432 | 0.144 |
| Marital: married | 0.500 | 0.500 | 0.417 | 0.493 | 0.167 | 0.451 | 0.498 | 0.344 | 0.475 | 0.215 |
| Marital: single | 0.500 | 0.500 | 0.583 | 0.493 | −0.167 | 0.549 | 0.498 | 0.656 | 0.475 | −0.215 |
| Child gender: female | 0.429 | 0.495 | 0.500 | 0.500 | −0.143 | 0.406 | 0.491 | 0.394 | 0.489 | 0.023 |
| Child gender: male | 0.571 | 0.495 | 0.500 | 0.500 | 0.143 | 0.594 | 0.491 | 0.606 | 0.489 | −0.023 |
| Reason: Med | 0.357 | 0.479 | 0.75 | 0.433 | −0.788 | 0.389 | 0.488 | 0.634 | 0.482 | −0.492 |
| Reason : Surg | 0.643 | 0.479 | 0.25 | 0.433 | 0.788 | 0.611 | 0.488 | 0.366 | 0.482 | 0.492 |
| No ADHD | 0.857 | 0.35 | 0.667 | 0.471 | 0.452 | 0.842 | 0.365 | 0.779 | 0.415 | 0.15 |
| ADHD | 0.143 | 0.35 | 0.333 | 0.471 | −0.452 | 0.158 | 0.365 | 0.221 | 0.415 | −0.15 |
| No anxiety disorder | # | # | 0.583 | # | # | # | # | # | # | # |
| Anxiety disorder | # | # | 0.416 | # | # | # | # | # | # | # |
| No Autism | 0.714 | 0.452 | 0.833 | 0.373 | −0.283 | 0.722 | 0.448 | 0.882 | 0.323 | −0.378 |
| Autism | 0.286 | 0.452 | 0.167 | 0.373 | 0.283 | 0.278 | 0.448 | 0.118 | 0.323 | 0.378 |
| No bipolar disorder | # | # | 0.916 | # | # | # | # | # | # | # |
| Bipolar disorder | # | # | 0.083 | # | # | # | # | # | # | # |
| No depression | 0.929 | 0.258 | 0.75 | 0.433 | 0.495 | 0.91 | 0.286 | 0.835 | 0.371 | 0.209 |
| Depression | 0.071 | 0.258 | 0.25 | 0.433 | −0.495 | 0.09 | 0.286 | 0.165 | 0.371 | −0.209 |
| No eating disorder | 0.929 | 0.258 | 0.833 | 0.373 | 0.298 | 0.939 | 0.238 | 0.762 | 0.426 | 0.556 |
| Eating disorder | 0.071 | 0.258 | 0.167 | 0.373 | −0.298 | 0.061 | 0.238 | 0.238 | 0.426 | −0.556 |
| No language disorder | 0.785 | # | # | # | # | # | # | # | # | # |
| Language disorder | 0.214 | # | # | # | # | # | # | # | # | # |
| No sleep disorder | 0.929 | 0.258 | 0.917 | 0.276 | 0.045 | 0.945 | 0.228 | 0.944 | 0.23 | 0.005 |
| Sleep disorder | 0.071 | 0.258 | 0.083 | 0.276 | −0.045 | 0.055 | 0.228 | 0.056 | 0.23 | −0.005 |

# = indicates no variability, *SD* = standard deviation.

Table 4 presents the results of the two regression models (weighted; doubly robust weighed) for each of the outcome measures. The models indicate non-significant but generally lower scores on both QTDS and CTM for the *e*PED group, reason for hospitalization (medical or surgical), and condition 6—eating disorder. The adjusted standardized mean difference of 0.554–0.775 is considered moderate to even large effects (Kelley & Preacher, 2012). The results indicate that exposure to the *e*PED has the potential to negatively influence QDTS and CTM scores compared to the usual care/comparison group.

**Table 4.** Group Effect Using Propensity Weighting.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Variable | Model 1: QDTS Weighted | Model 2a: QDTS Doubly Robust | Model 3 CTM: Weighted | Model 4a  CTM: Doubly Robust |
|  | b/se | b/se | b/se | b/se |
| *e*PED | −1.515 (0.93) | −1.67 (1.20) | −0.480 (0.34) | −0.499 (0.43) |
| Surgical vs. medical |  | 0.656 |  | 0.103 |
|  |  | (1.24) |  | (0.44) |
| Eating disorder |  | −0.085 |  | 0.025 |
|  |  | (0.83) |  | (0.27) |
| Constant | 9.655\*\*\* (0.14) | 9.422\*\*\*\* (0.42) | 2.951\*\*\* (0.10) | 2.905\*\*\* (0.19) |
| R-square | 0.103 | 0.120 | 0.081 | 0.083 |
| Degrees of freedom | 23 | 21 | 23 | 21 |
| BIC | 117.7 | 123.6 | 66.8 | 73.1 |
| Cohen’s *d* effect size | 0.775 | 0.691 | 0.626 | 0.554 |

*p* < .05, \*\**p* < .01 \*\*\**p* < .001; a = group effect with doubly robust propensity.

BIC = Bayesian Information criterion.

# Discussion

The purpose of this secondary analysis of a subset of the participants (parents of children with challenging behaviors) from a larger project was to compare parent perception of the quality of discharge teaching and care coordination when the nurse used the *e*PED app compared to the usual discharge without the app. In the study, the *e*PED app guided the nurse delivery of discharge teaching by structuring the discharge conversation. The questions on the *e*PED were designed to encourage parent engagement to plan for the safe care after discharge (Lerret et al., 2020; Weiss et al., 2017). In the larger study, parents who received teaching from nurses who used the *e*PED app reported higher quality of discharge teaching and care coordination than the usual care group (Lerret et al., 2020).

The results of this study were unexpected. While there were no statistical differences in mean scores on the outcome measure between *e*PED and control group parents, the effect size suggests the possibility that this approach to discharge teaching is not appropriate and does not produce the best results for this parent population of children with challenging behaviors. The preliminary evidence from the small sample of parents used for this analysis suggests that the use of the *e*PED app on the day of discharge may be associated with poorer parent perception of quality discharge teaching and care coordination. It appears that the *e*PED may not be a one size fits all discharge teaching intervention.

The findings are in contrast to the findings in the larger study. When parents do not perceive high-quality teaching and care transition they are not always able to provide the care needed for the child to recover. While these findings are specific to QDTS-D and CTM for this subset of parents, they may be indicative of broader issues not assessed but relevant to the hospital experience for parents of children with challenging behaviors. It may be that parents are either overwhelmed or have other stresses and as a result, their need to return to consistency or normalcy may outweigh the proposed benefits of using a structured app to enhance the discharge process.

There are many other reasons that parents of children with challenging behaviors may have perceived decreased quality of the delivery of the teaching and the care transition itself as compared to the usual care parents. While usual care involves the telling of information and provision of written instructions, nurses of parents who received teaching using the *e*PED app also needed to engage with them in planning additional supports at home. This teaching required thinking about who would help care for the child and who could they rely on for emotional support. In the larger project, it was this section of questions that the nurses had the most difficulty asking as it had not been part of typical information sharing in usual discharges (Lerret et al., 2020). Parents of children with challenging behaviors may already have caregiver strain and stress which could be further exacerbated by the hospitalization (missed work, other children at home, socioeconomic issues) and may have fewer resources available to them emotionally and physically (Vaughan et al., 2013). It may be that the probing questions on the *e*PED app increased the parent’s frustration or that nurses are not equipped with the answers or resources needed for these complex situations (Mitchell et al., 2018). There could also be a build-up of past experiences with hospital systems perceived as unhelpful that influence the current perception of quality of discharge teaching and transition (Vaughan et al., 2013).

In this study, the parents who received the usual care were able to leave the hospital faster since that *e*PED app required additional time to complete. The usual care parents of children with challenging behaviors may have felt less stigmatized by their child’s behaviors during the ePED-guided discharge, since it was a short discharge not involving questions about the home environment. In past studies, parents of children with challenging behaviors have reported feeling non-accepted and stigmatized by their inability to control their child’s behavior in public, which may lead parents to want to remove themselves from the hospital as soon as possible (Johnson, Sangasy, et al., 2020). It is also possible that the parents wanted to return to the home environment so that they could get back into their normal routine. Their children may have fewer challenging behaviors when back in their familiar home environment (Bultas et al., 2016; Johnson & Rodriguez, 2013; Johnson et al., 2013). The implementation of strategies in the hospital to limit the child’s frustration during transitions could positively support the discharge teaching experience between the parent and the nurse.

Parents of children with challenging behaviors may be more experienced with interacting with the health care system and may face additional challenges which can lower frustration threshold or modify what is needed at the time of discharge as compared to other parents. The differences are important given the AHRQ’s IDEAL discharge model (AHRQ, 2013) recommendation to include the patient and family, and listen to and honor goals, preferences, observations, and concerns of the family [IDEAL (AHRQ, 2013)].

This study has limitations. First, the study was not designed with randomization of children with challenging behaviors to the *e*PED implementation. Instead, data were collected about the child conditions and the analyses in this study were post hoc. The second limitation is small sample size and the number of covariates. However, the statistical modeling with the propensity scores and the double robust model allowed for analysis of differences between groups even with the small sample size. This method is a strength in the study. Interpretations in this study are made with caution due to small sample size, but may reflect unique differences for this patient population that prioritize further study.

Future studies are needed that implement enhanced training for nurses in the use of a modification of the *e*PED app with families of children with challenging behaviors or use of another intervention in place of the *e*PED. Given parent’s possible frustration from the probing questions, it will be important in future research to gauge the parent’s desire for the detailed discharge with the app, before utilizing this approach to discharge. Supplementing the *e*PED app with resources for the nurses on challenging behaviors to better equip them to answer parent questions for these complex situations could be a valuable enhancement to the *e*PED tool.

Another suggestion for future research is adding in focus groups with the implementation of the *e*PED in a larger sample of children with challenging behaviors would improve understanding about what parents need at the time of discharge. Randomized controlled trial design rather than post hoc analyses would also advance the state of the science. Given the gap in the literature on discharge for parents of children with challenging behaviors, a future mixed-method study with nurse role playing to prepare them for skilled discharge teaching is suggested. Furthermore, these parents may need preparation for discharge at a time other than the “last minute.” A focus group or individual interviews with parents clearly using qualitative methods to listen to the “unfiltered voices” of these parents is critical to creating appropriate discharge teaching and delivering it in a way that is most useful for the family. Other possible recommendations include connecting the *e*PED app to the electronic health record and hospital resources, and creating a module for complex needs of families of children with challenging behaviors.

Nurses are in a unique position of having the most interaction with the family during hospitalization. This time could incorporate the assessment for potential problems and connecting with appropriate resources (e.g., social work, respite care, and behavioral training programs) (Centers for Disease Control and Prevention, 2020). Development of an intervention that incorporates assessment of the unique needs that may exist for families of children with challenging behaviors would be beneficial. The information gained could also be used in the training of nurses (i.e., role playing with parents of children with challenging behaviors) and the provision of disease-specific resources that are unique to this population.

Timing of the discharge teaching must also be taken into consideration. While it is understood that discharge teaching should begin early in the hospitalization (Berry et al., 2014), prioritizing this or setting the expectation that there will be a day of discharge conversation using the *e*PED app may be useful.

The results of this study showed use of the ePED app to guide discharge teaching for the subset of parents of children with challenging behaviors was not perceived to be as helpful as usual care and that one size does not fit all for discharge teaching. Findings of this study are an important step in the understanding of the challenges and opportunities for nurses to engage parents of children with challenging behaviors at the stressful time of discharge.

Declaration of Conflicting Interests  
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding  
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the CTSI Pilot Collaborative Clinical and Translational Research Grants Program of the National Center for Advancing Translational Sciences (NCATS), National Institute of Health, Award Number UL1TR001436. Additional Funds were provided by The Pediatric Nursing Research Consortium of Milwaukee, a joint project of Marquette University College of Nursing, Children’s Wisconsin and the University of Wisconsin Milwaukee College of Nursing.

# References

|  |  |
| --- | --- |
|  | Agency for Healthcare Research and Quality . (2017). The teach back method. Retrieved August 10, 2019, from https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/interventions/teach-back.html |
|  | Agency for Healthcare Research and Quality . (2013). Strategy 4: IDEAL discharge planning (Implementation handbook): Care transitions from hospital to home: IDEAL discharge planning implementation handbook (guide to patient family engagement in hospital and quality safety). https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4\_Implement\_Hndbook\_508\_v2.pdf |
|  | Avni, E., Ben-Itzchak, E., Zachor, D. A. (2018). The presence of comorbid ADHD and anxiety symptoms in autism spectrum disorder: Clinical presentation and predictors. Frontiers in Psychiatry, 9, 717. https://doi.org/10.3389/fpsyt.2018.00717 |
|  | Bajorek, S. A., McElroy, V. (2020). Discharge planning and transitions of care. AHRQ. Retrieved Decemebr 30, 2020 from https://psnet.ahrq.gov/primer/discharge-planning-and-transitions-care |
|  | Berger, Z., Flickinger, T. E., Pfoh, E., Martinez, K. A., Dy, S. M. (2014). Promoting engagement by patients and families to reduce adverse events in acute care settings: A systematic review. BMJ Quality and Safety, 23(7), 548–555. https://doi.org/10.1136/bmjqs-2012-001769 |
|  | Berry, J. G., Blaine, K., Rogers, J., McBride, S., Schor, E., Brimingham, J., Schuster, M. A., Feudtner, C. (2014). A framework of pediatric hospital discharge care informed by legislation, research and practice. JAMA Pediatrics, 168(10), 955–996. https://doi.org/10.1001/jamapediatrics.2014.891 |
|  | Bultas, M. W., Johnson, N. L., Burkett, K., Reinhold, J. (2016). Translating research to practice for children with autism spectrum disorder: Part 2: Behavior management in home and health care settings. Journal of Pediatric Health Care, 30(1), P27–P37. https://doi.org/10.1016/j.pedhc.2015.09.009 |
|  | Cene, C. W., Johnson, B. H., Wells, N., Baker, B., Davis, R., Turchi, R. (2016). A narrative review of patient and family engagement: The “foundation” of the medical “home”. Medical Care, 54(7), 697–705. https://doi.org/10.1097/MLR.0000000000000548 |
|  | Centers for Disease Control and Pevention . (2020). Children’s mental health: Behavior or conduct problems in children. https://www.cdc.gov/childrensmentalhealth/behavior.html |
|  | Coleman, E. A., Mahoney, E., Parry, C. (2005). Assessing the quality of preparation for post-hospital care from the patient’s perspective: The care transitions measure. Medical Care, 43(3), 246–255. |
|  | Coleman, E. A., Smith, J. D., Frank, J. C., Eilertsen, T. B., Thiare, J. N., Kramer, A. M. (2002). Development and testing of a measure designed to assess the quality of care transitions. International Journal of Integrated Care, 2(1), 1–9. |
|  | Glasgow, R. E., Klesges, L. M., Dzewaltowski, P., Estabrooks, P. A., Vogt, T. M. (2006). Evaluating the impact of health promotion programs: Using the RE-AIM framework to form summary measures for decision making involving complex issues. Health Education Research, 21(5), 688–694. |
|  | Holmes, W., Olsen, L. (2010). Using propensity scores with small samples. Presented at the Meeting of the American Evaluation Association, San Antonio, TX. https://doi.org/10.13140/2.1.2255.0724 |
|  | Johnson, N. L., Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: A systematic review of the literature. Pediatric Nursing, 39(3), 131–141. |
|  | Johnson, N. L., Bekhet, A., Robinson, K., Rodriguez, D. (2013). Attributed meanings and strategies to prevent challenging behaviors of hospitalized children with autism: Two perspectives. Journal of Pediatric Health Care, 28(5), 386–393. https://doi.org/10.1016/j.pedhc.2013.10.001 |
|  | Johnson, N. L., Bree, O., Lalley, E. E., Rettler, K., Grande, P., Gani, M. O., Ahamed, S. I. (2014). Effect of a social script iPad application for children with autism going to imaging. Journal of Pediatric Nursing, 29(6), 651–659. https://doi.org/10.1016/j.pedn.2014.04.007 |
|  | Johnson, N. L., Lerret, S., Klingbeil, C. G., Polfuss, M., Gibson, C., Gralton, K., Garnier-Villarreal, M., Ahamed, S. I., Riddhiman, A., Unteutsch, R., Pawela, L., White-Traut, R., Sawin, K., Weiss, M. (2020). Engaging parents in education for discharge (ePED): Evaluating the reach, adoption & implementation of an innovative discharge teaching method. Journal of Pediatric Nursing, 54, 42–49. https://doi.org/10.1016/j.pedn.2020.05.022 |
|  | Johnson, N., Sangasy, P., Robinson, K. (2020). “No one could calm him down”: Mothers’ experience of autism diagnosis and obtainment of resources in an urban public school district. Families, Systems, and Health, 38(3), 255–264 https://doi.org/10.1037/fsh0000527 |
|  | Kelley, K., Preacher, K. J. (2012). On effect size. Psychological Methods, 17(2), 137–152. https://doi.org/10.1037/a0028086 |
|  | Koski, S., Gabriels, R. L., Beresford, C. (2016). Interventions for paediatric surgery patients with comorbid autism spectrum disorder: A systematic literature review. Archives of Diseases in Childhood, 101(12), 1090–1094. https://doi.org/10.1136/archdischild-2016-310814 |
|  | Lerret, S. M., Weiss, M. E. (2011). How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant. Pediatric Transplant, 15(6), 606–616. https://doi.org/10.1111/j.1399-3046.2011.01536.x |
|  | Lerret, S. M., Johnson, N. L., Polfuss, M., Weiss, M., Gralton, K., Klingbeil, C. G., Gibson, C., Garnier-Villarreal, M., Ahamed, S. I., Adib, R., Unteutsch, R., Pawela, L., White-Traut, R., Sawin, K. (2020). Using the engaging parents in education for discharge (ePED) iPad application to improve parent discharge experience. Journal of Pediatric Nursing, 52, 41–48. https://doi.org/10.1016/j.pedn.2020.02.041 |
|  | Lerret, S. M., Weiss, M. E., Stendahl, G. L., Chapman, S., Menendez, J., Williams, L., Nadler, M. L., Neighbors, K., Amsden, K., Cao, Y., Nugent, M., Alonso, E. M., Simpson, P. (2015). Pediatric solid organ transplant recipients: Transition to home and chronic illness care. Pediatric Transplant, 19(1), 118–129. https://doi.org/10.1111/petr.12397 |
|  | Lerret, S. M., Weiss, M. E., Stendahl, G., Chapman, S., Neighbors, K., Amsden, K., Lokar, J., Voit, A., Menendez, J., Alonso, E. M. (2014). Transition from hospital to home following pediatric solid organ transplant: Qualitative findings of parent experience. Pediatric Transplant, 18(5), 527–537. https://doi.org/10.1111/petr.12269 |
|  | Levy, S. E., Giarelli, E., Lee, L. C., Schieve, L. A., Kirby, R. S., Cunniff, C., Nicholas, J., Reaven, J., Rice, C. E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. Journal of Developmental Behavavioral Pediatrics, 4, 267–275. |
|  | McCaffrey, D. F., Griffin, B. A., Almirall, D., Slaughter, M. E., Ramchand, R., Burgette, L. F. (2013). A tutorial on propensity score estimation for multiple treatments using generalized boosted models. Statistics in Medicine, 32(19), 3388–3414. https://doi.org/10.1002/sim.5753 |
|  | McCaffrey, D. F., Ridgeway, G., Morral, A. R. (2004). Propensity score estimation with boosted regression for evaluating causal effects in observational studies. Psychological Methods, 9(4), 403–425. https://doi.org/10.1037/1082-989X.9.4.403 |
|  | Mitchell, S. E., Laurens, V., Weigel, G. M., Hirschman, K. B., Scott, A. M., Nguyen, H. Q., Howard, J. M., Laird, L., Levine, C., Davis, T. C., Gass, B., Shaid, E., Li, J., Williams, M. V., Jack, B. W. (2018). Care transitions from patient and caregiver perspectives. Annals of Family Medicine, 16(3), 225–231. https://doi.org/10.1370/afm.2222 |
|  | Perou, R. H., Bitsko, S. J., Blumberg, P., Pastor, R. M., Ghandour, J. C., Gfoerer, S. L. (2013). Mental Health surveillance among children - United States 2005–2011. Morbidity and Mortality Weekly Report. https://www.cdc.gov/mmwr/pdf/other/su6202.pdf |
|  | Ryan, P., Sawin, K. J. (2009). The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. Nursing Outlook, 57(4), 217–225 e216. https://doi.org/10.1016/j.outlook.2008.10.004 |
|  | Sawin, K. J., Weiss, M. E., Johnson, N., Gralton, K., Malin, S., Klingbeil, C., Lerret, S. M., Thompson, J. J., Zimmanck, K., Kaul, M., Schiffman, R. F. (2017). Development of a self-management theory-guided discharge intervention for parents of hospitalized children. Journal of Nursing Scholarship, 49(2), 202–213. https://doi.org/10.1111/jnu.12284 |
|  | StataCorp . (2019). Stata Statistical Software [Computer software]. StataCorp LLC. |
|  | Straus, J., Coburn, S., Maskell, S., Pappagianopoulos, J., Cantrell, K. (2019). Medical encounters for youth with autism spectrum disorder: A Comprehensive review of environmental considerations and interventions. Clinical Medicine Insights Pediatrics, 13, 1179556519842816. https://doi.org/10.1177/1179556519842816 |
|  | Sullivan, B., Ming, D., Boggan, J. C., Schulteis, R. D., Thomas, S., Choi, J., Bae, J. (2015). An evaluation of physician predictions of discharge on a general medicine service. Journal of Hospital Medicine, 10(12), 808–810. https://doi.org/10.1002/jhm.2439 |
|  | Tanner, C. A. (2006). Thinking like a nurse: A research-based model of clinical judgment in nursing. Journal of Nursing Education, 45(6), 204–211. |
|  | Tsiatis, A. A., Davidian, M. (2007). Comment: Demystifying double robustness: A comparison of alternative strategies for estimating a population mean from incomplete data. Statistical Science, 22(4), 569–573. https://doi.org/10.1214/07-STS227 |
|  | Vaughan, E. L., Feinn, R., Bernard, S., Brereton, M., Kaufman, J. S. (2013). Relationships between child emotional and behavioral symptoms and caregiver strain and parenting stress. Journal of Family Issues, 34(4), 534–556. https://doi.org/10.1177/0192513X12440949 |
|  | Weiss, M., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., Sherburne, E. (2008). Readiness for discharge in parents of hospitalized children. Journal of Pediatric Nursing, 23(4), 282–295. https://doi.org/10.1016/j.pedn.2007.10.005 |
|  | Weiss, M., Sawin, K. J., Gralton, K., Johnson, N., Klingbeil, C., Lerret, S., Malin, S., Yakusheva, O., Schiffman, R. (2017). Discharge teaching, readiness for discharge, and post-discharge outcomes in parents of hospitalized children. Journal of Pediatric Nursing, 34, 58–64. https://doi.org/10.1016/j.pedn.2016.12.021 |