Journal of Pediatric Nursing 69 (2023) 47–55

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Parental caregivers' perception of their transition from hospital to home in children with cerebral palsy who have undergone orthopedic surgery

Rachel L. DiFazio, PhD, RN, PPCNP-BC, FAAN [a,b,*], Patricia J. Miller, MS [a], David Geyer, MSN, RN [c], Benjamin J. Shore, MD, MPH, FRCSC [a,b], Brian D. Snyder, MD, PhD [a,b], Judith A. Vessey, PhD, MBA, RN, FAAN [d]

[a] Department of Orthopedic Surgery and Sports Medicine, Boston Children's Hospital, Boston, MA, United States of America
[b] Harvard Medical School, Boston, MA 02115, United States of America
[c] Boston College, Connell School of Nursing, Chestnut Hill, MA, United States of America
[d] Medical, Surgical, and Behavioral Health Programs, Boston Children's Hospital, Boston, MA 02115, United States of America

ARTICLE INFO

Article history:
Received 2 October 2022
Revised 29 November 2022
Accepted 22 December 2022

Keywords:
Cerebral palsy
Orthopedic procedures
Patient discharge,
Health resources
Transitional care
Continuity of care

ABSTRACT

Purpose: Evaluate parental perception of the quality of discharge teaching, readiness for discharge, and the impact of these on post discharge coping difficulty and resource utilization in children with cerebral palsy (CP) following surgery.

Design and methods: Prospective cohort study conducted from September 2017–March 2021 at a pediatric academic medical center. Demographics were collected pre-operatively. Parents completed the Readiness for Hospital Discharge Scale (RHDS) and Quality of Discharge Teaching Scale (QDTS) within four hours of discharge. Four weeks post-discharge, parents completed the Post-discharge Coping Difficulty Scale (PDCDS). Utilization of healthcare resources were extracted from the electronic health record for 90 days post-operatively. Associations among demographics, RHDS, QDTS, PDCDS and resource utilization were assessed using general linear models; PDCDS's open-ended questions were analyzed using directed content analysis.

Results: 114 parental caregivers participated. Post discharge coping was significantly associated with additional resource utilization: length of stay ($p = 0.046$), readmissions ($p = 0.001$), emergency department visits ($p = 0.001$), clinic calls ($p = 0.001$) and unplanned clinic visits ($p = 0.006$). PDCDS was negatively correlated with the QDTS *Quality of Teaching Delivered* subscale ($r = -0.32$; $p = 0.004$) and three of five RHDS subscales: 1) *Child's Personal Status* ($r = -0.24$; $p = 0.02$);'2) *Knowledge* ($r = -0.30$; $p = 0.005$); and 3) *Coping Ability* ($r = -0.39$; $p < 0.001$). Four themes explicated parental coping difficulties.

Conclusion: Parents experiencing coping difficulties were more likely to have difficulty managing their child's care needs at home and required additional health care resources.

Practice implications: Recognizing that parents' readiness for discharge may not reflect their coping abilities post-discharge requiring nurses to coordinate pre- and post-discharge education and support services.

Providing seamless transitions between the hospital and home is a daunting challenge for healthcare providers of children with complex chronic conditions including children with cerebral palsy (CP). Children with severe CP as a consequence of an insult to the developing brain have significant global delays in cognitive and motor development as well as associated medical co-morbidities (e.g. respiratory impairment, seizures, and gastroesophageal reflux) that contribute to lifelong functional limitations (Pruitt & Tsai, 2009; Vitrikas et al., 2020). These children are maximally dependent on their parents/caregivers for activities of daily living (dressing, toileting, hygiene) and mobility (Difazio, Vessey, Zurakowski, & Snyder, 2016; Stephens, 2005). Children with severe CP often require orthopedic surgeries to address fixed joint contractures affecting the appendicular skeleton, hip instability and spinal deformity (Flynn & Miller, 2002; Sarwick, 2000). Care needs are high after surgery and the post-operative recovery is frequently prolonged by medical co-morbidities that increase the risk for post-operative complications that require the utilization of additional health care resources including prolonged hospital stay, hospital readmission, emergency department visits, and unplanned clinic visits (DiFazio, Vessey, Miller, et al., 2016).

Most providers determine discharge readiness based on the child's physiologic stability rather than the readiness of the caregiver (Weiss et al., 2007). Discharge planning must include family readiness for the

* Corresponding author at: Department of Orthopedic Surgery and Sports Medicine, Boston Children's Hospital, 300 Longwood Ave., Boston, MA, United States of America.
E-mail addresses: Rachel.Difazio@childrens.harvard.edu (R.L. DiFazio), geyerd@bc.edu (D. Geyer).

https://doi.org/10.1016/j.pedn.2022.12.023
0882-5963/

burden of managing the complexities of surgical recovery as rehabilitation shifts from the health care team to the family (Weiss et al., 2008). When parents feel unprepared, they often have difficulty managing their child's complex care needs that are heightened in the transition from hospital to home (Lerret et al., 2015; Lerret & Weiss, 2011; Weiss et al., 2008). Elevated stress and difficulty coping often can result and can lead to further health care resource utilization (Holland et al., 2014; Poh et al., 2020; Weiss et al., 2008).

Underlying this issue is that a family's perception of their readiness for discharge may be different from that supposed by the health care team (Amin et al., 2016). In an effort to meet hospital quality standards while decreasing health care costs, healthcare providers are encouraged to shorten post-operative hospital stays. The use of standardized discharge planning processes helps achieve these goals. Failure to personalize information and include important steps such 'teach-back' of instructional content and demonstrations specific to the child's physical limitations and co-morbidities may be omitted. These parents, rarely neophytes in providing post-discharge hospital care, often perceive that they have received more than sufficient discharge instructions when teaching is done in this milieu (Lerret et al., 2015; Poh et al., 2020).

Failure to proactively assess the patient/family needs and to provide personalized education prior to hospital discharge undermines parents' sense of self-efficacy in being able to care for their child (Bajorek & McElroy, 2020). To assure an optimal transition from hospital to home, discharge readiness needs to incorporate individualized parental education designed to strengthen their self-efficacy, competency and comfort with providing post-operative care with the ultimate goal of improving post-discharge parental coping.

Purpose

Over the last three decades a body of descriptive literature has emerged underscoring the challenges parents of hospitalized children face, yet little information exists specifically evaluating the readiness of the parent/caregiver for their child's discharge. This dearth of information is particularly problematic in caring for children with medical complexity such as those with cerebral palsy where parents now must balance new post-operative demands with the child's underlying medical needs.

The purpose of this study was to assess the readiness of parents of children with CP for the transition from hospital to home following orthopedic surgery by investigating three specific aims: 1) determine if parent perceptions of the quality of discharge teaching, readiness for discharge, and post discharge coping affected the need for additional healthcare resources (i.e., length of stay, hospital readmission, emergency department visits, clinic calls and unplanned clinic visits); 2) determine if parental perception of the quality of discharge teaching and readiness for discharge correlate with parental coping difficulty after discharge; 3) determine if patient/parent demographics and patient clinical characteristics are associated with parental perceptions of readiness for discharge, quality of discharge teaching, and coping difficulty after discharge; and 4) explore the coping difficulties experienced by parents following transition from hospital to home.

Design and methods

Design

A longitudinal single group prospective cohort study was conducted with data collection across three time points: 1) pre-operative; 2) day of hospital discharge; and 3) 4 weeks post-operative. The study was conducted at a pediatric academic medical center in the northeast USA between September 2017 and March 2021. During this 4-year time period, the discharge preparation, discharge teaching and educational material have remained the same. The study was approved by the Institutional Review Board and informed consent was obtained from all study participants.

Theoretical framework

Meleis' middle-range theory of transitions provided the framework for this study and aided in the selection of variables. In Meleis's theory, transition is defined as a transition or transfer from one state, condition or place to another (Meleis, 2010; Schumacher & Meleis, 1994) and is fundamentally about the experience of human beings as they transition from one state of being to another (Meleis, 2010). Transition has an impact on health and can lead to poor outcomes. Transition from hospital to home following surgery is a critical time and patients/families can feel overwhelmed (Kelly et al., 2016): Meleis' theory has been widely applied to help explicate this phenomenon (Lerret, 2009; Zhan et al., 2022).

Variables in this study were mapped to major concepts in Meleis' Transition Theory (Meleis, 2010). 1) Transition nature refers to the surgical procedure, hospitalization and ultimately the transition from hospital to home. The study variables included the characteristics of the hospitalization such as admission type and length of stay. 2) Transition conditions refer to those personal and environmental circumstances that can have an effect on achieving a healthy transition. The study variables included the child/parent demographics and child clinical characteristics. 3) Patterns of response refer to patient's/caregiver's understanding of the situation and the strategies for managing the child's care. The study variables include readiness for hospital discharge, post-discharge coping difficulty and post-discharge health care utilization. 4) Nursing therapeutics focus on nursing action's that promote a healthy transition. In this study these include patient/caregiver education and care coordination related to learning the new roles and responsibilities required to care for the child at home. The study variables include quality of discharge teaching.

Sample

Participants were included if they met the following inclusion criteria: 1) parent of a child with non-ambulatory CP classified as Gross Motor Function Classification System (GMFCS) IV-V; 2) child age 3–20 years; 3) child scheduled for elective orthopedic surgery including single event multilevel surgery [SEMLS], reconstructive hip surgery, or spine fusion; 4) parent is the primary caregiver and cares for the child at home; and 5) parent speaks and reads English.

Instruments

Electronic health record data extraction worksheet

This investigator-developed worksheet was used to collect: 1) pertinent patient specific clinical data: GMFCS functional level, type of surgery, length of stay, medical co-morbidities, postoperative complications; and 2) additional resource utilization over the ensuing 90 days after discharge including emergency department visits, unscheduled clinic visits, clinic calls and readmissions.

Quality of Discharge Teaching Scale (QDTS)

This 18-item questionnaire measures caregiver perceptions of their educational preparation for discharge. Discharge teaching was conceptualized as a combination of all teaching received by the patient and family in preparation for their transition to home including but not limited to, nurses, nurse practitioners, surgeons and physical therapists. It has two subscales: 1) *Content Received* (6 items) measures the amount of information received specific to caring for the child at home, medical treatments and medications, when to call the provider, and specific family learning needs; and 2) *Quality of Teaching Delivery* (12 items) measures the healthcare providers' skill as educators and includes items on communication strategies, sensitivity to family values,

consistency of information provided, promotion of parents' self-efficacy in caregiving. Items are scored on a scale from 0 "none at all" to 10 "a great deal" with higher scores indicate higher quality of teaching (Weiss et al., 2010). The Cronbach's alpha reliability was 0.78 and 0.88 for the two respective subscales (Weiss et al., 2007).

Readiness for Hospital Discharge Survey (RHDS)

This 29-item questionnaire was used to assess parental perceptions of readiness for discharge. It contains 5 subscales: 1) *Parental Personal Status* (7 items)–how the caregiver feels at time of discharge; 2) *Child's Personal Status* (4 items)- how the child feels at time of discharge; 3) *Knowledge* (10 items)–how much the caregiver knows about discharge information related to the child's care at home; 4) *Perceived Coping Ability* (3 items)–how well the caregiver will be able to manage care demands at home; and 5) *Expected Support* (5 items)–how much help and emotional support is available at home. Two dichotomous items (Questions #1a and #1b) are not part of the scale score. These questions ask the caregiver if they are ready to take their child home and if they think that their child is ready to go home. Items are scored on a scale from 0 "not at all" to 10 "totally" with higher ratings indicating greater readiness. Cronbach's alpha for the subscales range from 0.7 to 0.86 (Weiss et al., 2008).

Post-discharge Coping Difficulty Scale (PDCDS)

An 11-item questionnaire, the PDCDS was used to assess attributes associated with post-discharge parental coping: difficulties with stress, recovery, self-care, self-medical management, family difficulty, help and emotional support needed, confidence in self-care and medical management capabilities and adjustment. Each item is scored on a scale from 0 "not at all" to 10 "extremely or a great deal"; total scores range from 0 to 100, with higher scores indicating greater coping difficulty. Question 6b "How much help had you expected to need?" is not included in the total score. Additionally five open-ended questions are included in this measure: 1) What has been stressful in your life?; 2) What has been difficult with your child's recovery?; 3) What has been difficult in caring for your child at home?; 4) What has been difficult about managing your child's medical condition?; and 5) What has been difficult about life for your family members or other close persons? Cronbach's alpha was 0.84 for the scale (Weiss et al., 2008).

Procedures

After receiving approval from the Institutional Review Board, informed consent was obtained by the research assistant. Parents completed the Demographic Worksheet at their child's pre-operative visit in the outpatient clinic. Following surgery patients and their families received standard discharge teaching by the healthcare team including but not limited to physicians, nurses, nurse practitioners, case managers, and physical therapists. Within 4 h of the child's discharge, the parent completed the RHDS and QDTS. The children were discharged to home with their caregiver/family. At the 4-week post-operative visit in the outpatient clinic, parents completed the PDCDS including providing written responses to the 5 open ended questions that are part of this instrument. At each data collection time point, parents completed the questionnaires in a private room and a member of the research team was available to answer any questions related to the study or completion of the questionnaires. The utilization of additional healthcare resources was captured through review of the child's electronic health record over the ensuing 90 days following the date of surgery. The decision to collect data for 90 days following surgery was based on previous published studies conducted in pediatric orthopedics (Fields et al., 2021; Lee et al., 2020; Roddy & Diab, 2017). In addition, this is the time period when caregivers have reported the greatest difficulty at home following hip and spine surgery (Difazio, Vessey, Zurakowski, & Snyder, 2016).

Data analysis

Power analysis

The primary research question is the effect of the quality of discharge teaching (QDTS) and readiness for hospital discharge (RHDS) on hospital readmission rate. Therefore, to detect a 50% reduction in the odds of readmission for a one standard deviation increase in the RHDS or QDTS or a doubling in the odds of readmission for a one standard deviation increase in the PDCDS, requires at least 128 subjects for a binary logistic regression model to achieve 80% power with alpha set to 0.05. With the 114 patients enrolled into this study, we achieved 94% power at the 5% significance level to detect the reported change in the probability of readmission for a one standard deviation increase in the mean score for the PDCDS.

Statistical methods

Patient and caregiver characteristics and outcome measures were summarized using descriptive statistics. Readmission rates were estimated along with a 95% confidence interval while length of stay and additional resource utilization were summarized by median and interquartile range. General linear modeling (including binary logistic, Poisson, and/or negative binomial regressions) were used to assess associations between RHDS subscale scores, QDTS subscale score, and PDCDS total score and need for additional healthcare resources. Pearson's correlation analysis was used to assess the relationships between each of RHDS subscale scores, QTDS subscale scores, and PDCDS total score. Multivariable general linear modeling was used to assess the relationships between RHDS subscale scores, QTDS subscale scores, PDCDS total score and child/caregiver demographic and clinical factors. Directed content analysis following the approach described in Hsieh and Shannon (2005) was used to examine the qualitative responses to the open-ended questions on the PDCDS. Two independent reviewers (RLD and DG) categorized the qualitative data and arrived at consensus.

Results

Demographics

A total of 114 children and their caregivers participated. The average age of the children was 12 years, SD = 4.9. Over half of the children were male ($n = 67$, 59%), the majority being white ($n = 92$, 81%) and non-Hispanic ($n = 96$, 84%). Ninety-two percent ($N = 104$) of the children were non-ambulatory, categorized as GMFCS IV or V (Palisano et al., 2008). The median length of stay for this cohort was 6 days (IQR, 5–11). After hospital discharge, 78 children (68%; 95% CI [59, 77] required additional healthcare resources within 90 days of surgery The average age of the caregivers was 42 years ±10.2. Sixty three percent ($n = 72$) of the caregivers had a college education and more than half ($n = 61$, 61%) worked either part or full time outside of the home. A full description of the child and parental caregiver demographics and characteristics of the child's clinical course are provided in Table 1.

Summary statistics

Parents/caregivers reported that the quantity of content they received in preparation for discharge was slightly above the midpoint for the QDTS's *Content Received* subscale items (M = 6.1, SD = 2.0). The quality of teaching presentation was rated moderately high as indicated by the *Quality of Teaching Delivery* subscale items (M = 8.7, SD = 1.3). On the RHDS's two summary yes/no questions (1a, 1b) parents ($n = 99$) reported that they felt ready to go home ($n = 95$; 96%) and that their child was also ready to go home (n = 99; 96%). Parents' perceptions of readiness for discharge as represented by the scores on the RHDS's subscale were above the median score in four out of five of the subscales: 1) *Parental Personal Status* (M = 5.7, SD = 0.6); 2) *Knowledge*

Table 1
Child and caregiver demographics ($N = 114$).*

Child Characteristics	Freq.	(%)
Age at surgery (*years; mean (SD)*)	12	(4.9)
Gender (*% male*)	67	(59%)
Race		
White	92	(81%)
Black or African American	14	(12%)
American Indian or Alaskan native	1	(1%)
Asian or Pacific Islander	4	(4%)
Other or Unknown	3	(3%)
Ethnicity (Non-Hispanic)	96	(84%)
GMFCS (Gross Motor Function Classification Scale) Level		
GMFCS III	9	(8%)
GMFCS IV	54	(47%)
GMFCS V	51	(45%)
Orthopedic diagnosis		
Spastic Hip Dysplasia	79	(69%)
Neuromuscular Scoliosis	35	(31%)
Distal Femoral Osteotomy	3	(3%)
Comorbidities		
Speech/Non-verbal	81	(71%)
Cortical stability/Seizure Disorder and/or hydrocephalus	79	(69%)
Feeding and Swallowing/G-tube	72	(63%)
Respiratory function/Sleep Apnea	40	(35%)
Caregiver Characteristics		
Age (*years; mean (SD)*)	42	(10.2)
Education level		
Some high school or less	8	(7%)
High school diploma/GED	14	(12%)
Some college, vocational school or associates degree	20	(18%)
College or university degree	42	(37%)
Post graduate degree	30	(26%)
Work status		
Working full time (40+ hours)	37	(33%)
Working part time (1–39 h)	24	(21%)
Full time homemaker	14	(12%)
Not working due to my child's health	24	(21%)
Not working for other reasons	9	(8%)
Retired	3	(3%)
Unknown	3	(3%)
Family income		
Less than $20,000	4	(4%)
$20,000–$34,999	11	(10%)
$35,000–$49,999	8	(7%)
$50,000–$74,999	21	(18%)
$75,000–$99,999	14	(12%)
$100,000–$149,999	23	(20%)
$150,000–$199,999	13	(11%)
$200,000 or more	12	(11%)
Declined to answer	1	(1%)
Unknown	7	(6%)
Distance from Home to Hospital	60	(30–100)
Clinical Characteristics		
Length of hospital stay (*days; mean (SD)*)	6	(5–11)
Readmission	22	(19%)
Emergency Room (ER) visit	29	(25%)
Unplanned outpatient clinic visit	31	(27%)
Clinical call to outpatient clinic staff	65	(57%)
Post-operative Immobilization Devices		
Petrie Casts	1	(1%)
Knee Immobilizers	64	(56%)
Abduction Wedge	62	(54%)
Spinal Orthosis	1	(1%)
Short leg casts	16	(14%)
Mapleleaf Brace	7	(6%)
Other	8	(7%)
None	33	(29%)

SD, standard deviation; GMFCS, gross motor function classification scale.
* Children may have more than one post-operative immobilization device; therefore, the total percentage is >100%.

($M = 8.7$, $SD = 1.26$); 3) *Perceived Coping Ability* ($M = 8.6$, $SD = 1.4$); and 4) *Expected Support* ($M = 7.2$, $SD = 2.8$), with the exception being *Child's Personal Status* subscale ($M = 4.3$, $SD = 1.2$) which was below the median score. Knowledge and perceived coping ability were rated the highest by parents. However, parental coping abilities four weeks after discharge were low (PDCDS $M = 56.1$, $SD = 18.1$).

Table 2
Associations between the PDCDS and Resource Utilization.

Outcome	N	Mean	(SD)	N	*r*	(95% CI)	P
Length of stay	101	56.1	(18.1)	101	0.20	(0–0.38)	0.046
	Resource Utilization			No Resource Utilization			
Questionnaire	N	Mean	(SD)	N	Mean	(SD)	P
Readmission	20	67.7	(19.6)	81	53.2	(16.7)	0.001
Emergency department visit	23	66.6	(18.8)	78	53.0	(16.8)	0.001
Unplanned clinic visit	29	63.7	(15.3)	72	53.0	(18.4)	0.006
Clinic call	71	59.9	(17.6)	30	46.9	(16.3)	0.001
Any outcome	58	59.7	(18.2)	43	51.1	(17.0)	0.02

PDCDS, the Post-discharge Coping Difficulty Scale; SD, standard deviation; CI, confidence interval.

Aim #1 results

There were no significant associations detected between the subscales of the QDTS and RHDS questionnaires and the need for additional healthcare resources. However, post discharge coping difficulty (PDCDS) was significantly associated with the need for additional healthcare resources: length of stay ($p = 0.046$), readmission ($p = 0.001$), emergency department visits ($p = 0.001$), unplanned clinic visits ($p = 0.006$) and clinic calls ($p = 0.001$). For each additional unit of PDCDS the odds of a return event increased by 5% (OR = 1.05; 95% 95% CI [1.02, 1.08]; $p = 0.002$), independent of any child/caregiver demographics or clinical characteristic (Table 2).

Aim #2 results

A small (10%) but significant negative correlation was detected between the PDCDS and the QDTS *Quality of Teaching Delivery Subscale* ($r = -0.32$; $p = 0.004$), however no correlation was detected between the QDTS *Content Received Subscale* ($p = 0.36$) and the PDCDS. Examining correlations between the RHDS subscales and the PDCDS, 3 of the 5 subscales were negatively correlated with the PDCDS: 1) *Child's Personal Status* ($r = -0.24$; $p = 0.02$), 2) *Knowledge* ($r = -0.30$; $p = 0.005$), and 3) RHDS *Coping Ability* ($r = -0.39$; $p < 0.001$). No significant correlation existed between the RHDS subscales: 1) *Parent's Personal Status* ($p = 0.94$) and 2) *Expected Support* ($p = 0.06$) and the PDCDS (Table 3).

Aim #3 results

Lower family income was associated with an increase in the quantity of content received ($r = -0.26$; 95% CI [0.45, −0.05]; p = 0.02), an increase in parental perceptions of their child's readiness for discharge ($r = -0.37$; 95% CI [0.54, −0.18]; p < 0.001), and an increase in expected support (r = −0.26; 95% CI [0.44, −0.06]; $p = 0.01$). Lower

Table 3
Correlation on the QDTS and RHDS with PDCDS.

Questionnaire	N	*r*	(95% CI)	P
Quality of Discharge Teaching Scale (QDTS)				
Content Received Subscale	90	−0.104	(−0.32–0.12)	0.36
Quality of Teaching Delivery Subscale	89	−0.319	(−0.51–0.1)	0.004
Readiness for Hospital Discharge Survey (RHDS)				
Parent's Personal Status Subscale	96	0.009	(−0.2–0.22)	0.94
Child's Personal Status Subscale	97	−0.243	(−0.43–0.03)	0.02
Knowledge Subscale	100	−0.295	(−0.48–0.09)	0.005
Perceived Coping Ability Subscale	101	−0.389	(−0.55–0.2)	0.00
Expected Support Subscale	101	−0.203	(−0.39–0.01)	0.06

PCDS, the Post-discharge Coping Difficulty Scale; CI, confidence interval.

parental education attainment was associated with an increase in perceived child readiness at discharge ($r = -0.33$; 95% CI [−0.50, −0.14]; $p = 0.001$), and an increase in expected support ($r = -0.28$; 95% CI [−0.45, −0.09]; $p = 0.005$) and an increase in PDCDS score, where higher scores indicate greater coping difficulty ($r = -0.25$; 95% CI [−0.42, −0.05]; $p = 0.01$). Decreased patient age was associated with an increase in expected support ($r = -0.28$; 95% CI [−0.45, 0.0]; $p = 0.049$). There were no significant associations detected among child, caregiver, and clinical characteristics and the likelihood of requiring additional healthcare resources.

No significant associations were detected among QDTS and RHDS scores at hospital discharge and post-discharge medical resource utilization. However, parental coping difficulty, as measured by the PDCDS at the 4-week post-operative visit, was significantly associated with the need for additional medical resources: length of stay ($p = 0.046$), hospital readmission ($p = 0.001$), emergency department visits ($p = 0.001$), clinic calls ($p = 0.001$) and unplanned clinic visits ($p = 0.006$). Decreased parent education level was associated with an increased PDCDS score, where higher scores indicate greater coping difficulty ($r = -0.25$; 95% CI [−0.42, −0.05]; $p = 0.01$). Furthermore, the PDCDS was negatively correlated with the QDTS *Quality of Teaching Delivered* subscale ($r = -0.32$; $p = 0.004$) and three of five RHDS subscales: 1) *Child's Personal Status* ($r = -0.24$; $p = 0.02$); 2) *Knowledge* ($r = -0.30$; $p = 0.005$); 3) *Coping Ability* ($r = -0.39$; $p < 0.001$).

Aim #4 results

The etiology of the coping difficulties faced by parental caregivers' was extracted from their answers on the five open-ended questions on the PDCDS. These results illuminated the challenges that families encountered following discharge of their child from hospital to home. Four themes emerged from the directed content analysis (Table 4).

Theme 1: The presence of pain and its ramifications

Parents voiced concerns related to the unmitigated musculoskeletal pain experienced by their child and their ability to manage it once at home. The pain experienced by their child and the parental concerns it elicited are captured in the following quotes: "constant pain once the numbness wore off;" "seeing her in so much pain;" "staying on top of the pain during the night;" "it (pain management) was well explained but difficult calibrating pain meds for a nonverbal child;" and "pain was the most difficult aspect of his recovery."

Theme 2: Management of care routines

Many parents expressed difficulty adjusting to and coping with new care routines. These difficulties negatively impacted family life and were captured in the following quotes: "changing diapers and keeping his brace clean (was arduous);" "I needed a second person to help with most care;" "getting little sleep and still expected to do all necessary duties;" and "do not have enough time for other family members and children."

Theme 3: Additional post-operative needs

Poor vertical integration of home care resources exacerbated stress and altered family dynamics was also problematic. The following quotes listed specific issues that parents encountered: "coordinating services and stuff to assist at home;" "competent in-home help was not available;" and "home health aides are not allowed to do enough to be helpful."

Theme 4: Altered family dynamics

The transition from hospital to home affected the family routine. Parental frustrations were noted in the following quotes: "Trying to continue working and taking care of his needs;" "More is required from them as I need to help managing care;" "Not being able to go out as a family;" "The family did not realize the impact of us not being as 'mobile' post-op. We are a baseline an active family so this was hard;" and "being stuck in home with no good way to transport child."

Discussion

Children with complex chronic conditions such as CP require extensive health care resources and caregiving for all activities of daily living, yet there is a paucity of research addressing these children's needs after major surgery and their transition from hospital to home (Auger et al., 2014). This study, which prospectively addresses discharge readiness, parental coping and resource utilization begins to fill this gap. Its findings lay the ground work for future study designed to meet the specialized post-operative discharge planning needs of children with CP and other complex chronic conditions. Promoting successful transition from the hospital to home is multifaceted.

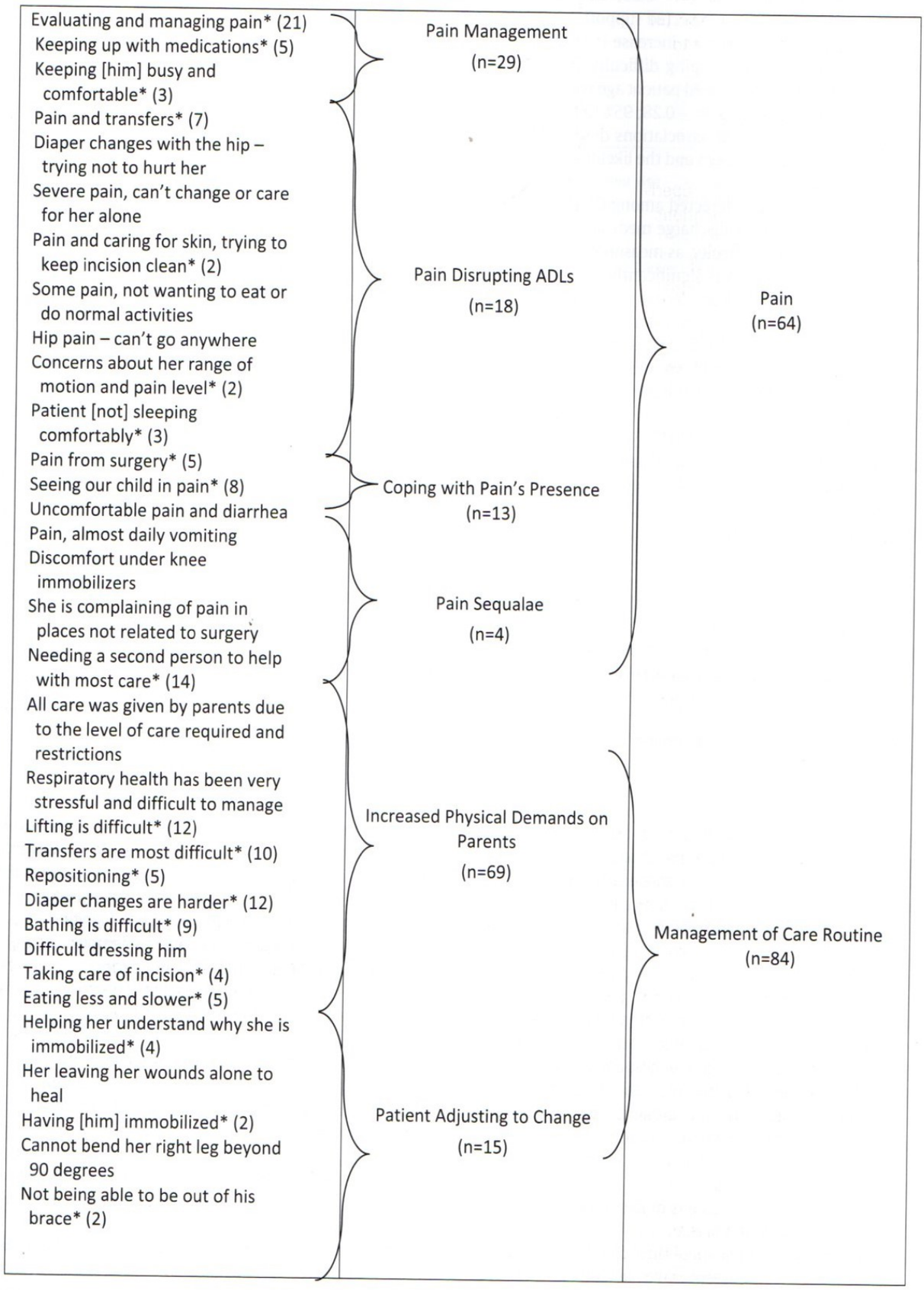
The purpose of this work was to assess the effect of discharge teaching on parents' perceptions of discharge readiness, post discharge coping and additional health care resource utilization following orthopedic surgery in non-ambulatory children with CP. Ideally, effective discharge planning and teaching would result in better parental coping and less need for additional healthcare resources following hospital discharge. However, the results of this study indicate that parents' perceptions regarding the quality and quantity of discharge teaching and their (and their child's) readiness for discharge assessed at the time of hospital discharge did not influence the subsequent need for additional healthcare resources. As this study focused solely on non-ambulatory children with severe CP, these parents already had extensive experience and self-efficacy in managing their child's physical limitations and medical comorbidities, which frequently involved multiple hospitalizations. A similar study of children 0–18 years from varied racial/ethnic, health status, socio-economic backgrounds, and surgical interventions also found that parental readiness did not predict additional resource utilization over the 3 weeks following discharge home including: calls to friends and family for advice, calls to providers, calls to the hospital, unscheduled office or clinic visits, urgent care/ER visits and hospital readmission (Weiss et al., 2008).

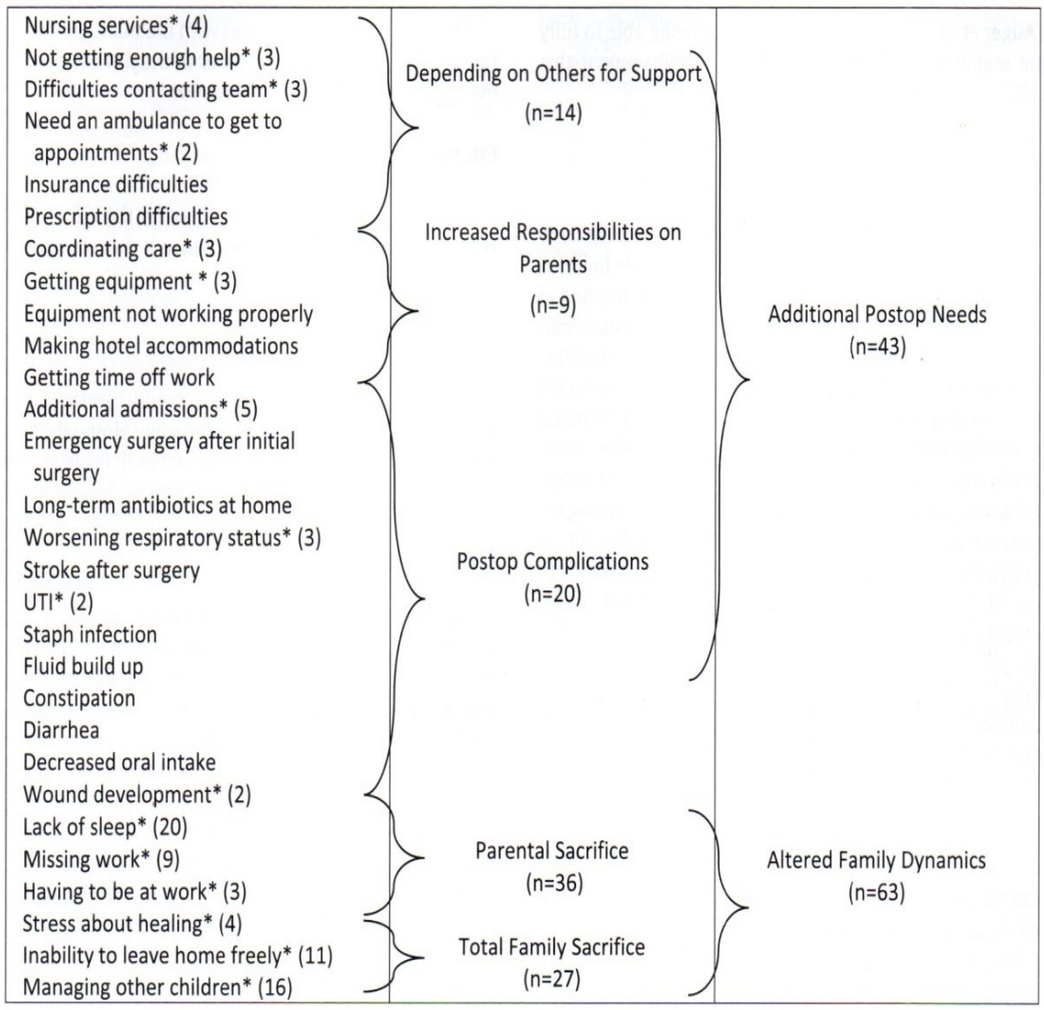
Discharge teaching is predicated on standardized protocols and printed educational material, but typically does not incorporate nor is personalized to account for parental expertise. Delivery of discharge teaching varies based on the nurses' clinical experience and pedagogical abilities (Johnson et al., 2020). Effective pedagogy, which influences learning, requires that all educational domains—cognitive (i.e., understanding the material), psychomotor (i.e., able to demonstrate necessary skills), and affective (believing in one's capabilities)—be addressed (Donlan, 2018). Deficits in the quantity or quality of discharge information content were not an issue, as parents reported receiving more content than needed.

No significant associations were detected among caregiver demographics, patient clinical characteristics and additional resource utilization. Interestingly both decreased family income and decreased parent education were associated with an increase in parental perceptions of their child's readiness for discharge as well as an increase in expected support. Decreased family income was associated with an increase in the quantity of content received. Possible explanations for this include an emphasis on individualizing care for families from diverse backgrounds, and coming from a catchment area with more robust public insurance programs and services than seen nationally. An alternative explanation is that these families were less able to predict their child's care needs post-discharge as had been demonstrated in other studies (Auger et al., 2021).

Daily caregiver burdens for parents of children with complex medical conditions such as severe CP are significantly more pronounced following surgery (DiFazio, Vessey, Miller, et al., 2016; Difazio, Vessey, Zurakowski, & Snyder, 2016). Specific strategies need to be developed for the areas of coping difficulty identified by the parents. These areas include pain management, care routines and family life.

Table 4
Codes, categories and themes from open ended questions on PDCDS.





* Denotes statement was reported by multiple parents.

The presence of pain and its ramifications is the predominant concern for parents following their child's discharge across all age, developmental, and surgical categories (Chabot & Ferland, 2020; Longard et al., 2016). For parents of children with CP, this concern is heightened due to comorbidities including spasticity and limited verbal status. Effective pain management requires that parents understand the differences between in-patient pain management protocols that use peripheral nerve blocks and/or intravenously administered analgesics (NSAIDS, narcotics) and anti-spasmodic versus in-home enteral pain management protocols to decrease musculoskeletal pain symptomatology. With the current emphasis on decreasing the length of hospitalization, the transition to enterally administered analgesics prior to discharge is accelerated, often without optimization. The didactic and psychomotor components of pain management—symptom identification; medication selection, dosage, onset of action and administration; and weaning from narcotics—are emphasized with less discussion of mitigating the sequelae of the child's pain (and side effects of treatment) on activities of daily living for both the child and parent.

The physical and temporal demands of their child's post-discharge care routines and the impact they have on family life often underestimated by parents. Parents in this study as well as others have found performing the child's activities of daily living while balancing other family needs was physically exhausting and emotionally complex placing parental well-being and family stability at risk for deterioration (Alzawad et al., 2022; Koch et al., 2021; Lerret et al., 2014). Successful transition from hospital to home is facilitate by developing a well-coordinated continuum of care. Beginning at the time of pre-operative consultation, parents need to be explicitly instructed to consider social support and availability of help with physical tasks following discharge. Individualized planning can assist with ensuring that needed resources are available to the family following their child's discharge from the hospital.

Readiness for discharge is still primarily determined by provider judgement and frequently influenced by utilization reimbursement parameters (Brittan et al., 2015). Comprehensive discharge management requires an institutional commitment to ensuring that appropriate infrastructure and suitably expert human resources are provided for discharge screening, planning, teaching, and post-discharge follow up. Nursing staff shortages, higher nurse to patient ratios, younger and less experienced nurses all adversely affect the quality of discharge teaching (Weiss et al., 2017). Notwithstanding the current emphasis on shared decision-making, little has changed in the last several decades to promote parental psychological readiness for their child's hospital discharge (Considine et al., 2020). To promote the successful transition of patients and their families from the hospital to home requires fostering parental readiness and perceived self-efficacy. Intervention research has emphasized the importance of a multifaceted approach that encompasses the method of content delivery, timing of teaching, provider pedagogical expertise, and facilitated coordination of home health care services. Standardized protocols for delivering information such as checklists are championed to improve the consistency and quality of discharge planning and education, but must be adopted with care (Berry et al., 2014). Successful delivery of information requires that nurses and other health care providers communicate compassionately to develop a trusting relationship with the family. Promoting an open dialog personalizes the discharge teaching and can strengthen parental attributes requisite for effective coping and successful home management which embrace self-efficacy, resilience, and problem-solving

capabilities (Auger et al., 2014). However, without being able to fully appreciate the reality of the family's culture and environment this may be difficult.

Practice implications

Nurses are pivotal to a families' successful transition from hospital to home. Preparing nurses and providing appropriate structures to facilitate discharge planning (standardized information content, method of teaching, timing of teaching, provider pedagogical expertise, and facilitated pre-discharge coordination of home health care services) will improve parental discharge readiness and strengthen parental attributes (self-efficacy, resilience, and problem-solving capabilities) requisite for laying the foundation for effective coping and successful home management of medically complex children. The parents' ability to cope with the post-discharge transition is critical. In addition to teaching related to competence and skill building, nurses should help families to develop the supports systems requisite to dealing with disruptions to care routines and family life. Targeted follow-up post-discharge including telephone contact by an experienced nurse should be considered so that the specific physical and emotional difficulties encountered by families can be addressed at their inception. Combined these efforts will improve the quality of care, decrease healthcare resource utilization and ultimately improve clinical outcomes.

Limitations

Generalizability may be limited as data were collected from a single pediatric medical center which may not reflect the experiences of all patient/parent - health care system dyads at other hospitals. In addition, the vast majority of the study population were white, non-Hispanic which does not reflect the population of children with CP. Discharge teaching was completed by multiple clinical staff (surgeons, nurses, nurse practitioners, case managers, social workers, physical therapist) - using various methods of teaching, distinct information content and different criteria for discharge readiness predicated on their specific area of expertise. No information related to the duration of teaching, information reviewed, assessment of the parents' baseline knowledge of care before and comprehension after teaching were measured. Data for resource utilization were extracted from the electronic health record, unless specified in the electronic health record at a follow up visit, it was not always possible to determine whether additional resources were utilized outside the institution. No data was collected on home services and aides available and actually used by families. Thus, it is unknown if additional home services and/or aides would have improved parental coping. Addressing these limitations will serve as the basis for a more comprehensive prospective study.

Conclusions

Parents in this study expressed difficulties with coping after hospital discharge following orthopedic surgery performed in non-ambulatory children with CP. Beyond the resultant family stress, additional healthcare resource utilization was noted. These findings reflect the challenges faced in providing family-centered discharge teaching in today's hospital milieu with its emphasis on high-quality, cost-effective care. Over the past two decades, findings from a significant body of research have explicated the challenges parents face and have posited nurse-led strategies to address them. However, new demands to reduce patient length of stays and an emerging shortage of experienced pediatric nurses juxta positioned with emerging technologies appropriate for integration into discharge teaching and transition home requires the reexamination of strategies that promote post-operative discharge readiness.

Dr. DiFazio was not involved with the management of the review of this manuscript. Another member of the JPN Editorial Team provided oversight with the manuscript review.

Ethical conduct of research

This research study was approved by the IRB at Boston Children's Hospital, Boston, MA. Informed consent was obtained from all study participants.

Funding source

This study was supported by the Inquiry Investment Drives Evidence into Action (IDEA) Grant, Boston Children's Hospital. The funding source had no role in the study design, data collection, analysis and interpretation of date, writing the report and decision to submit for publication.

Credit statement

Rachel DiFazio: Responsible for the conceptualization, methodology and data collection for the study. Assisted with statistical analyses. Wrote initial draft of manuscript, incorporated all suggested edits by research team and accepted final version for submission.

Patricia Miller: Completed the quantitative analysis for the manuscript, wrote a draft of the statistical analysis for the manuscript and reviewed and accepted final submission.

David Geyer: Assisted with the qualitative analysis and generation of the themes, edited the manuscript and accepted final submission.

Benjamin Shore: Assisted with recruitment and data collection, edited the manuscript and accepted the final submission.

Brian Snyder: Assisted with recruitment and data collection, edited the manuscript and accepted the final submission.

Judith Vessey: Assisted with the conceptualization, methodology and data collection for the study. Edited the manuscript and accepted the final submission.

Declaration of Competing Interest

The authors have no conflicts of interest relevant to this article to disclose.

References

Alzawad, Z., Lewis, F. M., & Walker, A. (2022). Parents' challenges beyond the pediatric intensive care unit: Fraying at the seams while balancing between two worlds, home and hospital. *Children*, 9, 267. https://doi.org/10.3390/children9020267.

Amin, D., Ford, R., Ghazarian, S. R., Love, B., & Cheng, T. L. (2016). Parent and physician perceptions regarding preventability of pediatric readmissions. *Hospital Pediatrics*, 6 (2), 80–87. https://doi.org/10.1542/hpeds.2015-0059.

Auger, K. A., Kenyon, C. C., Feudtner, C., & Davis, M. M. (2014). Pediatric hospital discharge interventions to reduce subsequent utilization: A systematic review. *Journal of Hospital Medicine*, *9*(4), 251–260. https://doi.org/10.1002/jhm.2134.

Auger, K. A., Sucharew, H. J., Simmons, J. M., Shah, S. S., Kahn, R. S., & Beck, A. F. (2021). Differential impact of home nurse contact after discharge by financial strain, primary care access, and medical complexity. *Hospital Pediatrics*, *11*(8), 791–800. https://doi.org/10.1542/hpeds.2020-004267Bajorek.

Bajorek, S. A., & McElroy, V. (2020). *Discharge planning and transitions of care.* AHRQ Patient Safety Network Retrieved from: https://psnet.ahrq.gov/primer/discharge-planning-and-transitions-care.

Berry, J. G., Blaine, K., Rogers, J., McBride, S., Schor, E., Birmingham, J., ... Feudtner, C. (2014). A framework of pediatric hospital discharge care informed by legislation, research, and practice. *JAMA Pediatrics*, *168*, 955–966. https://doi.org/10.1001/jamapediatrics.2014.891.

Brittan, M., Albright, K., Cifuentes, M., Jimenez-Zambrano, A., & Kempe, A. (2015). Parent and provider perspectives on pediatric readmissions: What can we learn about readiness for discharge? *Hospital Pediatrics*, *5*, 559–565. https://doi.org/10.1542/hpeds.2015-0034.

Chabot, B., & Ferland, C. E. (2020). Inpatient postoperative undesirable side effects of analgesics management: A pediatric patients and parental perspective. *Pain Reports*, *5* (5). https://doi.org/10.1097/PR9.0000000000000845.

Considine, J., Berry, D., Sprogis, S. K., Newnham, E., Fox, K., Darzins, P., ... Street, M. (2020). Understanding the patient experience of early unplanned hospital readmission

following acute care discharge: A qualitative descriptive study. *BMJ Open*, *10*, Article e034728. https://doi.org/10.1136/bmjopen-2019-034728.

DiFazio, R., Vessey, J. A., Miller, P., Van Nostrand, K., & Snyder, B. (2016). Postoperative complications after hip surgery in patients with cerebral palsy: A retrospective matched cohort study. *Journal of Pediatric Orthopaedics*, *36*, 56–62. https://doi.org/10.1097/BPO.0000000000000404.

Difazio, R. L., Vessey, J. A., Zurakowski, D., & Snyder, B. D. (2016). Differences in health-related quality of life and caregiver burden after hip and spine surgery in non-ambulatory children with severe cerebral palsy. *Developmental Medicine & Child Neurology*, *58*(3), 298–305. https://doi.org/10.1111/dmcn.12872.

Donlan, P. (2018). Developing affective domain learning in health professions education. *Journal of Allied Health*, *47*, 289–295.

Fields, M. W., Lee, N. J., Ball, J. R., Boddapati, V., Mathew, J., Hong, D., ... Lenke, L. G. (2021). Spinal fusion in pediatric patients with marfan syndrome: A nationwide assessment on short-term outcomes and readmission risk. *European Spine Journal*, *30*(3), 775–787. https://doi.org/10.1007/s00586-020-06645-8.

Flynn, J., & Miller, F. (2002). Management of hip disorders in patients with cerebral palsy. *Journal of the American Academy of Orthopaedic Surgeons*, *10*, 198–209. https://doi.org/10.5435/00124635-200205000-00006.

Holland, D. E., Conlon, P. M., Rohlik, G. M., Gillard, K. L., Tomlinson, A. L., Raadt, D. M., ... Rhudy, L. M. (2014). Developing and testing a discharge planning decision support tool for hospitalized pediatric patients. *Journal for Specialists in Pediatric Nursing*, *19*(2), 149–161. https://doi.org/10.1111/jspn.12064.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*, 1277–1288. https://doi.org/10.1177/1049732305276687.

Johnson, N. L., Lerret, S., Klingbeil, C. G., Polfuss, M., Gibson, C., Gralton, 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.

Kelly, K. N., Noyes, K., Dolan, J., Fleming, F., Monson, J. R., Gonzalez, M., ... Doster, A. (2016). Patient perspective on care transitions after colorectal surgery. Journal of Surgical *Research*, *203*(1), 103–112. https://doi.org/10.1016/j.jss.2016.02.011.

Koch, A., Kozhumam, A. S., Seeler, E., Docherty, S. L., & Brandon, D. (2021). Multiple roles of parental caregivers of children with complex life-threatening conditions: A qualitative descriptive analysis. *Journal of Pediatric Nursing*, *61*, 67–74. https://doi.org/10.1016/j.pedn.2021.03.0170882-5963.

Lee, N. J., Fields, M. W., Boddapati, V., Cerpa, M., Dansby, J., Lin, J. D., ... Lenke, L. (2020). The risks, reasons, and costs for 30-and 90-day readmissions after fusion surgery for adolescent idiopathic scoliosis. *Journal of Neurosurgery: Spine*, *34*(2), 245–253. https://doi.org/10.3171/2020.6.SPINE20197.

Lerret, S. M. (2009). Discharge readiness: An integrative review focusing on discharge following pediatric hospitalization. *Journal for Specialists in Pediatric Nursing*, *14*(4), 245–255. https://doi.org/10.1111/j.1744-6155.2009.00205.x.

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 Transplantation*, *15*, 606–616. https://doi.org/10.1111/j.1399-3046.2011.01536.x.

Lerret, S. M., Weiss, M. E., Stendahl, G., Chapman, S., Neighbors, K., Amsden, K., ... Alonso, E. M. (2014). Transition from hospital to home following pediatric solid organ transplant: Qualitative findings of parent experience. *Pediatric Transplantation*, *18*(5), 527–537. https://doi.org/10.1111/petr.12269.

Lerret, S. M., Weiss, M. E., Stendahl, G. L., Chapman, S., Menendez, J., Williams, L., ... Simpson, P. (2015). Pediatric solid organ transplant recipients: Transition to home and chronic illness care. *Pediatric Transplantation*, *19*, 118–129. https://doi.org/10.1111/petr.12397.

Longard, J., Twycross, A., Williams, A. M., Hong, P., & Chorney, J. (2016). Parents' experiences of managing their child's postoperative pain at home: An exploratory qualitative study. *Journal of Clinical Nursing*, *25*(17–18), 2619–2628. https://doi.org/10.1111/jocn.13307.

Meleis, A. I. (2010). *Transitions theory: Middle range and situation specific theories in nursing research and practice*. New York: Springer.

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2008). Content validity of the expanded and revised gross motor function classification. *Developmental Medicine & Child Neurology*, *50*, 744–750. https://doi.org/10.1111/j.1469-8749.2008.03089.x.

Poh, P. F., Lee, J. H., Loh, Y. J., Tan, T. H., & Cheng, K. K. F. (2020). Readiness for hospital discharge, stress, and coping in mothers of children undergoing cardiac surgeries: A single-center prospective study. *Pediatric Critical Care Medicine*, *21*(5), e301–e310. https://doi.org/10.1097/PCC.0000000000002276.

Pruitt, D. W., & Tsai, T. (2009). Common medical comorbidities associated with cerebral palsy. *Physical Medicine and Rehabilitation Clinics of North America*, *20*(3), 453–467. https://doi.org/10.1016/j.pmr.2009.06.002.

Roddy, E., & Diab, M. (2017). Rates and risk factors associated with unplanned hospital readmission after fusion for pediatric spinal deformity. *The Spine Journal*, *17*(3), 369–379. https://doi.org/10.1016/j.spinee.2016.10.008.

Sarwick, J. (2000). New strategies and decision making in the management of neuromuscular scoliosis. *Orthopedic Clinics of North America*, *38*, 485–496. https://doi.org/10.1016/j.ocl.2007.07.001.

Schumacher, K. L., & Meleis, A. L. (1994). Transitions: A central concept in nursing. *Image: The. Journal of Nursing Scholarship*, *26*(2), 119–127. https://doi.org/10.1111/j.1547-5069.1994.tb00929.x.

Stephens, N. (2005). Complex care packages: Supporting seamless discharge for child and family. *Paediatric Nursing*, *17*, 30–32. https://doi.org/10.7748/paed2005.09.17.7.30.c1002.

Vitrikas, K., Dalton, H., & Breish, D. (2020). Cerebral palsy: An overview. *American Family Physician*, *101*(4), 213–220.

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*, 282–295. https://doi.org/10.1016/j.pedn.2007.10.005.

Weiss, M., Yakusheva, O., & Bobay, K. (2010). Nurse and patient perceptions of discharge readiness in relation to postdischarge utilization. *Medical Care*, *482-486*. https://doi.org/10.1097/MLR.0b013e3181d5feaeno.

Weiss, M. E., Piacentine, L. B., Lokken, L., Ancona, J., Archer, J., Gresser, S., ... Vega-Stromberg, T. (2007). Perceived readiness for hospital discharge in adult medical-surgical patients. *Clinical Nurse Specialist*, *21*, 31–42. https://doi.org/10.1097/00002800-200701000-00008.

Weiss, M. E., Sawin, K. J., Gralton, K., Johnson, N., Klingbeil, C., Lerret, S., ... 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.

Zhan, L. J., He, Y. C., Liu, Q. J., Pei, M. Y., Yu, L. X., & Liu, X. Y. (2022). Progress in the application of Meleis transition theory in the nursing field. *Nursing Communication*, *6*, Article e2022016. https://doi.org/10.53388/IN2022016.