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IMPROVING CAREGIVER COPING AND REDUCING RECIDIVISM WITH A PEDIATRIC BURN DISCHARGE EDUCATION TOOLKIT

by

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Table of Contents

IMPROVING CAREGIVER COPING AND REDUCING RECIDIVISM WITH A PEDIAT	RIC
BURN DISCHARGE EDUCATION TOOLKIT	1
Acknowledgments	2
Abstract	4
Improving Caregiver Coping and Reducing Recidivism with a Pediatric Burn Discharge	
Education Toolkit	5
References	19
Appendix A	23
Step-by-Step Instructions for "Wet to Dry" Burn Dressing Change	23

Abstract

In 2015, 4,506 children from 0-19 years of age were hospitalized with burn injuries in the United States (Center for Disease Control and Prevention, 2017). From 2013-2014, 325 out of 11,940 pediatric burn patients discharged from US facilities had unscheduled readmissions within 30 days (Wheeler et al., 2018). Adequate discharge education and quality of transitions from hospital to home will help prevent negative health outcomes and readmissions (Braet, Weltens, Bruyneel, & Sermeus, 2016). In this quality improvement project, caregivers of pediatric burn patients were assessed on their day of discharge with the Readiness for Hospital Discharge Scale (RHDS)- Parent Form (Weiss & Piacentine, 2006), received individualized discharge education, a burn-specific discharge education toolkit, and two follow-up phone calls. A Post-Discharge Coping Difficulty Scale (PDCDS) (Fitzgerald Miller, Piacentine and Weiss, 2008) was administered during the caregivers' second follow-up phone call. Role theory guided this project as education was provided to help caregivers with their new role of caring for their child's burn at home. Five parent/child dyads were included. The caregivers (mothers and fathers) scored a mean of 248.4 ± 32.16 out of 290 on the RHDS-Parent Form, with 290 representing complete readiness for discharge. Two weeks after discharge, parents scored a mean of 30.2 ± 20.1 on the PDCDS, with 100 indicating the greatest coping difficulty. During the three-month data collection from April-June 2019, there were 16 admitted pediatric burn patients with two readmissions during the month of May. No patients who received toolkits were readmitted, compared to 2/11 who did not receive toolkits. The distribution of toolkits was feasible and provided parents with necessary tools to care for burns at home.

Keywords: pediatric burns; caregiver coping; discharge toolkit; written discharge education; discharge education; hospital to home; discharge readiness; role theory

Improving Caregiver Coping and Reducing Recidivism with a Pediatric Burn Discharge Education Toolkit

The most commonly reported burns in the United States are scalds, contact burns or flame burns (World Health Organization, 2018). These types of burns can result in prolonged hospitalization, disfigurement, and extreme pain. Burns are the fifth most common cause of injuries that occur during childhood that are non-fatal (WHO, 2018). In 2015, 4,506 children from 0-19 years of age were hospitalized with burn injuries in the United States (Center for Disease Control and Prevention, 2017).

From 2013-2014, 325 out of 11,940 pediatric burn patients discharged from US facilities had unscheduled readmissions within 30 days (Wheeler et al., 2017). Based on this recidivism data, the transition from hospital to home is not always successful. Thus, a comprehensive discharge plan should identify gaps in caregiver knowledge and determine the readiness of caregivers who will be taking care of the hospitalized child at home (Lerret & Weiss, 2011). Problem Statement

Prior to this quality improvement project, parents of pediatric burn patients at an urban pediatric hospital received non-standardized verbal instructions during their child's dressing changes and received generalized written instructions about burn care prior to discharge. Upon discharge, the bedside nurse provided dressing change supplies; the contents and quantity were based on the nurse's judgement. There was no measurement of readiness for discharge and no post- discharge follow-up phone. Throughout the literature, it has been demonstrated that providing patients and caregivers with supplemental education and measuring readiness for discharge improves patient outcomes after hospitalization (Lerret & Weiss, 2011; Thomson, Cunningham & Hunt, 2001; Wallace, Perkhounkova & Bohr, 2018 ;).

Purpose

The purpose of this project was to implement standardized written discharge teaching for pediatric burn patients. The project's specific aims were to measure their readiness for discharge, individualize di0scharge education, improve caregiver coping at home, and reduce recidivism (hospitalization and urgent visits) related to burn care.

Literature Review

The literature provides evidence for thorough discharge education to improve readiness for hospital discharge and prevent hospital readmissions or ED visits and increase post-discharge coping. More specific evidence supported the use of illustrations and/or pictures as part of the discharge education to augment verbal instructions, measuring readiness for discharge and supporting families with telephone follow-up phone calls to measure coping difficulty after discharge.

Multiple investigators have implemented transitional care improvements to decrease readmissions (Braet, Weltens, Bruyneel, & Sermeus, 2006; Rice, Hillstrom, Barnes, Rastogi & Steinkeler, 2016; Zeller, Nair & McComskey, 2018). Braet et al. (2006) found that adequate discharge education and quality transitions from hospital to home prevented negative health outcomes and readmissions. Zeller, Nair and McComskey (2018) focused on patient education, discharge readiness and early intervention in a pilot program to decrease readmissions. The investigators implemented a discharge readiness tool, post-discharge follow-up phone calls and created a center where patients could be seen urgently if needed.

Multiple investigators have studied the effect of providing the patient and/or caregiver with supplemental education for referral at home (Ardebili et al.,2017; Delp & Jones, 1996; Kools, van de Wiel, Ruiter & Kok, 2006; Thomson, Cunningham & Hunt, 2001). Written, visual tools, videos and other multimedia material have been effective in patients with a low literacy (Ardebili et al., 2017).

Kools et al. (2006) investigated the effect of pictures included in instructions for medical devices. The investigators found that pictures had positive effects on the participants' recall and quality of performance when asked to demonstrate the instructions on video. Thomson et al. (2001) developed a questionnaire to compare the effectiveness of written, verbal and visual methods of providing orthodontic information.

Delp and Jones (1996) conducted a randomized controlled trial which showed that patients were more likely to read discharge instructions with illustrations (98% vs 79%, p < 0.001) than those without. Ardebili et al. (2017) investigated in a randomized controlled trial the effect of multimedia education (books and educational resources) in burn patients. Quality of life was measured through telephone calls, once before discharge and three months after the intervention.

Galvin, Wills, and Coffey (2017) conducted a systematic review on readiness for discharge. The investigators analyzed 24 articles and identified the consequences, antecedents, and attributes of being prepared for the discharge home as: physical stability, adequate support, physiological ability, and adequate information and knowledge. The authors concluded that practitioners who assessed readiness for discharge had a better understanding to assist patients to become ready for hospital discharge. Wallace, Perkhounkova, and Bohr (2018) and LaManna et al. (2016) both implemented studies using Readiness for Hospital Discharge Scales (RHDS) (patient and registered nurse forms), Care Transitions Measure (CTM-15) and a Post Discharge Coping Difficulty Scale (PDCDS) to measure quality of preparation for post-hospital care and assess the transition outcomes of patients.

The challenges of the transition to care at home following discharge have been well documented in qualitative and quantitative research. The quality of transitional care from hospital to home has shown positively affect post-discharge outcomes (Weiss et al., 2008; LaManna, Bushy; Lerret & Weiss, 2011; Wallace, Perkhounkova, & Bohr, 2018).

Using randomized control trials, multiple investigators have demonstrated the effects of follow-up phone calls in improving patient outcomes in a variety of populations. These include decreasing anxiety symptoms and post-traumatic stress (Goncalves, et al., 2016), reducing the number of issues after hospital discharge that ultimately reduced unnecessary burden on the community health system (Clari et al., 2015), and identifying concerns regarding medication management and follow-up appointments (Miller & Schaper, 2015). Follow-up phone calls were shown to reduce pain and complications in pediatric tonsillectomy patients when calls were delivered on postoperative days 1, 3, 5 and 10 (Paquette et al., 2013).

Conceptual Framework

Role Theory (Biddle, 1979) was used to guide this project. This perspective emerged in the late 1920s and the early 1930s through several disciplines. Biddle described several important components of role theory, including individuals' roles, identities, and behaviors. Each role has specific expectations for role behavior and how the individual in the identified social position (mother, father, teacher, nurse) should perform their roles/duties (Biddle, 1979). Major (2003) utilized role theory to help employed parents cope with children's chronic illness. This author developed strategies to meet the needs of the ill child, allow the parents to maintain their physical and mental health and enabled parents to continue meeting the demands of their other roles outside of the home. Major recognized the need for effective role negotiation and balanced coping strategies that would allow parents to successfully maintain employment and taking care of a child with a chronic illness.

For pediatric burn patients, the mother, father and/or guardian are typically filling the role of caregiver of a child with a burn. Their role expectation is to promote physical and psychological healing, prevent the child from having any adverse effects, and to help the child re-emerge in a lifestyle that is minimally affected by the burn incident or consequences. To perform these duties successfully, parents and/or guardians need support to transition the child from the acute care setting with formal caregivers to the home setting with informal family or community caregivers.

At the same time, parents/guardians may have multiple role demands beyond caring for the child who has experienced a burn. Such role demands can be identified through the RHDSparent form and subsequently included in the discharge education. Pertinent discharge education for the parent/guardian and child can maximize the potential of the informal caregiver to help the child in his/her recovery, well-being, and quality of life.

Setting and Organizational Assessment

This project was conducted in an urban inpatient pediatric hospital on *medical-surgical* units that primarily care for pediatric post-operative, telemetry, and burn patients. There were 130 pediatric burn patients admitted from January 2017 to September 2018. With the known history of inpatient burn patient census on these units, it was expected that the project sample

would include caregivers of 15-20 patients. The primary caregiver for each child was included in the sample to assure that each patient was only represented once in the sample. Staff Involvement

There was little staff involvement in the development of this quality improvement project. An email was sent to all staff members notifying them of the project. The student project leader posted signs at all of the nursing stations (six total) to request that the bedside nurse taking care of the patient would call the student project leader for pending discharges. The surgery nurse practitioners also notified the student project leader of any pending discharges. The student project leader would then arrive to the hospital to deliver a discharge education toolkit, a Readiness for Hospital Discharge Scale, and to set them up for their follow-up phone calls.

Based on the scale responses, staff nurses and the project leader developed a teaching plan, assembled the home supplies needed for the toolkit, and the student project leader assisted in delivering the discharge teaching. Permission was granted from the Nurse Manager, Surgery Providers and the institution's research council to conduct the quality improvement project. A burn committee is in the process of implementation for sustenance of the project. The environment was open and willing to participate in quality improvement for the patients. Permissions

Permission was granted from the Nurse Manager, surgery providers, and the institution's research council to conduct the quality improvement project. The project received approval as a quality improvement project from the University of Louisville Institutional Review Board (IRB). The use of the pediatric burn discharge education toolkit is expected to be an ongoing practice; however, data for this project were collected for a three-month period.

Intervention

The primary caregivers of pediatric burn patients were assessed with a Readiness for Hospital Discharge Scale (Weiss & Piacentine, 2006) on the day of the planned discharge by the student project leader. Results from this scale directed the discharge nurse and student project leader on the type and amount of education needed for home care and the amount of supplies needed. They received a burn discharge education toolkit before discharge and received two follow-up phone calls after discharge. Patients are typically scheduled for a follow-up office visit one week after discharge.

The intervention was set up in three phases. The first phase occurred on the day of discharge. The caregiver received the RHDS-Parent Form and the Burn Discharge Education Toolkit. During the second phase, the caregiver received a follow-up phone call from the student project leader. During this phone call, the caregiver was asked generalized follow-up questions. During the last phase, the caregiver received a second phone call two weeks post-discharge and the PDCDS was delivered.

The Readiness for Hospital Discharge Scale

All caregivers were advised of the quality improvement project scope and procedures. The RHDS- parent form was administered to identify caregivers' and patients' level of pain or discomfort, energy, stress level, perceived physical ability, medical needs, knowledge of problems to watch for and medical treatments, and emotional support at home. The RHDSparent form data were kept in a secured lock box in the assistant nurse manager's office.

The responses to the RHDS- parent form were carefully examined to target why caregivers felt they were not able to care for their child's burn at home or education that needs clarification. Any negative responses on the RHDS-parent form were communicated with the patient's physician and follow up actions were set in place to ensure that they were ready to be discharged.

The project was developed and implemented through close consultation with the nurse manager of the pediatric units. An email was sent to all staff members notifying them of the project. The project leader posted signs at all of the nursing stations (six total) to request that the bedside nurse taking care of any burn patients call the project leader for pending discharges. The surgery nurse practitioners also notified the project leader of any pending discharges. The project leader administered the RHDS.

Based on the RHDS outcomes, staff nurses and the project leader collaborated to develop an individualized teaching plan, assemble the home supplies needed for the toolkit, and deliver the discharge teaching. The project leader arranged the follow-up phone calls for assessment of home care and administration of the Post- Discharge Coping Difficulty Scale (PDCDS). The timing of the phone calls was to intentional provide support in between discharge and their scheduled follow-up office visit.

The Burn Discharge Education Toolkit

Each caregiver was given the burn discharge education toolkit. The toolkit included individualized burn supplies based on the patient's percentage of body surface burned and discharge dressing change protocol, written and illustrated dressing change instructions, an index card with the surgery provider's 24-hour hotline phone number, and the *Burn Information for Families, What You Need to Know* booklet.

The Burn Information for Families: What you Need to Know, is a booklet developed by the University of Louisville Pediatric Surgery Physicians. It includes information on: healthy skin, descriptions of burns, burn classifications, pain control, specific treatments for burns,

nutrition, preventing future burns, major and minor burn care, and burn support and resources. This booklet provides supplemental written education for the caregivers and patients to prevent scars, contractures, and other adverse complications. The booklet provides suggestions to make the transition home easier and lays out examples of signs that the child may not be adjusting. Contact phone numbers for caregivers are included.

Follow-Up Phone Calls

The project leader conducted two follow-up phone calls. Three to five days after discharge, the caregiver used a script to assess home care (patient's pain management, follow- up appointment scheduled, reinforcement of discharge instructions, the patient's nutrition and hydration status, and seeking signs that the patient may not be adjusting and need to be seen by the provider sooner than planned). Two weeks following hospital discharge, the project leader conducted a second phone call to administer the PDCDS. If the caregiver would have scored positive for difficult coping, the surgery provider would have been notified by the project leader. Data from all phone contacts were kept in a secured lock box in the assistant nurse manager's office.

Participants

The target sample was caregivers of pediatric patients with body surface burns who were being discharged to their homes. All caregivers were at least 18 years old, resided with the child, and had enough English language knowledge to read and comprehend discharge teaching materials. Caregivers had access to a telephone for the two follow-up phone calls. Patients/ and or caregivers who expressed religious or philosophical opposition to recommended burn care would have been excluded.

Data Collection

Data were collected using a demographic form, the RHDS-Parent Form, PDCDS, and electronic health records for recidivism. All the data forms were kept in a locked box in the assistant nurse manager's office. Participant identifiers were kept in a separate folder. Measures

Readiness for Hospital Discharge Scale (RHDS- Parent Form)

Within 24 hours of discharge, parental readiness and learning needs were measured with the RHDS-Parent Form. The RHDS- parent form (Weiss and Piacentine, 2006), a 29-item scale which measures the caregiver's and child's personal status, knowledge, coping ability, and expected support at home. The RHDS- Parent Form includes 21 items from the master version of the RHDS and eight additional items are added to direct the scale toward parents (Weiss et al.,2008). Initial reliability and construct validity were examined by using confirmatory factor analysis and contrasting group comparisons of the master version RHDS. The authors reported a Cronbach's alpha of 0.90. Weiss and Piacentine (2006) and Weiss et al., (2008) reported a

In the 28 Likert-type items, respondents are asked about their readiness for returning home. Reponses range from 0-10; higher scores indicate greater readiness for discharge. Total scores ranges from 0-290. The 28 RHDS- Parent Form represent five subscales (Parent Personal Status, Child Personal Status, Knowledge, Coping Ability, and Expected Support); two dichotomous items ask about parent and child readiness to go home.

Weiss et al., (2008) concluded that parental readiness for discharge was associated with less coping difficulty, which in turn resulted in decreased recidivism. In a longitudinal study, Weiss et al. (2017) delivered the PDCDS on the day of discharge and found that readiness was negatively associated with coping difficulty at home (B=-0.52). The RHDS- parent form had a reported mean score of 8.74 ± 0.97 and a Cronbach's alpha of 0.89 in this study. (Weiss et al., 2008)

Post-Discharge Coping Difficulty Scale (PDCDS)

Post- Discharge parental coping was measured with the PDCDS. (Fitzgerald Miller, Piacentine and Weiss, 2008) which measures coping difficulty two weeks after discharge from an inpatient hospitalization. The 11 coping items are scored 0 (not at all) and 10 (extremely). Item 6b is not included in the score but used for a comparison of item 6a (amount of help needed verses amount of help expected). Thus, the total scores represent 10 items, ranging from 0-100 with 100 indicating the greatest coping difficulty. The scale has a Cronbach's alpha reliability for the parent sample of 0.84.

Items in the PDCDS measure multiple difficulties that parents often experience after a child's hospitalization, including: stress, recovery, self-care, self-medical management abilities, family difficulty, need for help and emotional support, confidence in self-care, and medical management abilities and adjustments (Fitzgerald Miller, Piacentine & Weiss, 2008).

The PDCDS scale was used by Fitzgerald Miller, Piacentine and Weiss (2008) in a descriptive cross-sectional study to determine the nature of coping difficulties through brief telephone interviews two to three weeks after discharge. The mean parental score was 23.0, indicated a relatively low level of coping difficulty. The authors provided evidence on qualitative findings about: specific stressors, topics that have been most difficult, the ability to care for self and managing medical condition, family support, the need to call family for additional support, needing to call the MD or use emergency services, and what the patients wished they had known.

Results

Sample Description

SPSS v. 26 was used to analyze data. Five parent/child dyads were included in the project. The majority of caregivers were females (80%) with the mean age of caregivers being 34 ± 3 years. The majority of patients were males (80%) with the mean age of 2.5 ± 1.8 years. The patients were either burned with a hot liquid (80%) or burned from fire (20%). Bacitracin (40%), Silvadene (40%), and Aquaphor (20%) were the three topical agents used for burn care. The average length of stay was 5.68 ± 8 days.

The caregivers (mothers and fathers) scored a mean of 248.4 ± 32.16 out of 290 on the RHDS-Parent Form, with 290 representing complete readiness for discharge. Two weeks after discharge, parents scored a mean of 30.2 ± 20.1 on the PDCDS, with 100 indicating the greatest coping difficulty. A review of electronic health records indicated that there were a total of 16 pediatric burn patients admitted from April-June 2019. None of the five who received the toolkit were readmitted; two of the 11 patients who did not receive the toolkit were readmitted. Both of these children had second-degree burns, one on the chest and the other on head, face, and neck. Out of the 16 patients admitted during the project period, only two patients had burns involving less than 10% of body surface.

Discussion

Interpretation

The pediatric burn discharge toolkit provided families of the burned child comprehensive resources at home. The RHDS- Parent Form helped to identify the caregivers' and patients' perceived readiness for discharge and taking care of the pediatric burned patient. The two follow-up phone calls provided support to the caregiver, the ability to express concerns about burn care, and the opportunity to relay their own coping ability. For example, one caregiver was a single mother had to change her son's burn dressings alone with no home support. She stated many times during the follow-up phone calls that she appreciated the support following their discharge. Another participant called immediately after leaving the hospital reporting that she lost her written discharge prescriptions for the patient. She was very concerned, but the student project leader was able to guide her to the appropriate phone number to be able to get the prescriptions.

One item on the RHDS-Parent Form determines how much a caregiver knows about services and information available in the community. This item helped to identify the lack of community services for burn patients and their caregivers. There were no negative unintended consequences, but additional thought can now be given to educating caregivers about community services available.

Limitations

This project relied on notification of pending discharges. There were 11 patients that were not included in the toolkit protocol because the project leader was not notified during pending discharges by bedside discharge nurses. To combat this possible limitation, repeat emails and reminders were sent out to the bedside nurses. Additionally, a new surgical protocol implemented on some burn patients required a to return to the hospital for providers to change burn dressings. This eliminated home dressing changes by primary caregivers, and thus, made these children ineligible for the project protocol. This new provider practice occurred at nearly the same time as the project implementation and resulted in the exclusion of five patients.

Lack of human subjects protection training and the need to maintain project data confidentiality limited the bedside nurses from delivering the discharge education toolkits and administering the RHDS-Parent Form. Future use of this discharge protocol as a standard of care will eliminate the human subjects training requirements. There was a much smaller participant sample that expected, which restricted the data analysis to descriptive evaluation only. Sustainability

A burn committee is being established on the pediatric units to continue the use of the pediatric burn discharge education toolkit as a standard of nursing practice. There are always improvements that can be made for discharge education and post-discharge follow up. Measuring individual readiness for discharge in the hospitalized pediatric patients allows nurses to target discharge education, and can reduce complications after discharge, especially when extensive care needs to be continued at home by a parent or caregiver.

Conclusion

The continued use of the pediatric burn discharge education toolkit will give the families of the burned child comprehensive resources for home care. The RHDS- Parent Form helped to identify the caregivers' and patients' perceived readiness for discharge and identified the caregivers' stress, physical ability, emotional readiness/support, expected help at home, and the ability to handle the demands of taking care of the pediatric burned patient. Targeted education followed. The two follow-up phone calls provided support to the caregiver and the ability to express concerns about burn care and relay their own coping ability. This intervention provided the opportunity to individualize discharge teaching and reduced potential complications that lead to recidivism.

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Appendix A

Step-by-Step Instructions for "Wet to Dry" Burn Dressing Change

Pediatric Burn Discharge Education Toolkit

Step-by-Step Instructions for "Wet to Dry" Burn Dressing Change

- Gather all supplies needed for dressing change, choose a designated spot for dressing change, either in the bath tub or on the couch/bed.
- Perform hand hygiene and ensure that the dressing change area has been properly cleaned. Pre-mediate patient with prescribed pain regimen at least 30 minutes before dressing change.
- Set up dressing change supplies on a table for easy access during the dressing change. Normal Saline or tap water to wet the fluffs to clean the burns.



4. Unwrap the bandage roll and take off the fluffs to expose the burn.



- After taking off bandage roll and fluffs, either place child in bathtub or use fluffs that have been in normal saline to clean the burns.
- While cleaning the burns, remove any dead skin to allow the non-burned skin underneath the ability to grow. Remove the old Silvadene or Bacitracin that was placed on the burn on the prior dressing change.
- 7. After the burns look clean and everything has been wiped down with the fluffs, take the Silvadene or Bacitracin and apply a thin layer to the skin that has been burned. Be careful not to put the Silvadene on the non-burned areas which can cause irritation. Silvadene (Silver sulfadiazine) is a 1 percent silver-based cream that has antimicrobial properties. Bacitracin is a topical antibiotic ointment used primarily on the face or minor burns. This may be used on the burn after it is healed but needed to keep moist. This can either be a prescription or anyone can get this over the counter at a drug store.



- 8. Once the prescribed ointment has been applied, place the dry fluffs over the burned area.
- 9. Then, place the bandage roll over top of the fluffs to secure them in place and then place tape to secure the roll. Bandage roll usually can be cut, and another part can be saved for next dressing change. Be sure to keep in a clean plastic bag. The burns should be changed two times a day (usually morning and evening) unless specifically told otherwise from surgery team.



References:

Taped bandage roll over burned area [Personal photograph taken at Norton Children's Hospital]. (2018, October 27).

Bandage roll [Personal photograph taken at Norton Children's Hospital]. (2018, October 27).

Dry fluffs to place over top the ointment [Personal photograph taken at Norton Children's Hospital]. (2018, October 27).

Normal Saline [Personal photograph taken at Norton Children's Hospital]. (2018, October 27).

Fluffs wet with normal saline [Personal photograph taken at Norton Children's Hospital]. (2018, October 27).

WebMD image retrieved on 10/29/2018 from: https://www.webmd.com/drugs/2/drug-966/bacitracin-zinc-topical/details

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