A Content Analysis of Emergency Department Discharge Instructions for Acute Pediatric Febrile Illnesses: The Current State and Opportunities for Improvement

Journal of Patient Experience Volume 8: 1-7 © The Author(s) 2021 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/23743735211060773 journals.sagepub.com/home/jpx SAGE

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Abstract

Quality emergency department (ED) discharge communication is critical to understanding of disease progression, home management, and return instructions. Addressing social aspects of disease burden are important to improving satisfaction and healthcare utilization. The objective of this study was to understand the extent to which written ED discharge instructions address multifaceted aspects of disease to meet the comprehensive needs of families with common childhood illnesses. We analyzed a national sample of 28 written discharge instructions from pediatric EDs using thematic and inductive content analysis. Seven themes were identified. Nearly all discharge instructions devoted a majority of content to themes related to disease physiology. Other themes common to instructions were related to parental instructions for caring for the child and when to return for further care. Content on caregiver reassurance, returning to daily activities, improving well-being, and promoting community health were not a focus of discharge instructions. Inclusion of multifaceted discharge materials which address both medical and social aspects of disease may help improve family-centered emergency care and the quality of care transitions for common childhood illnesses.

Keywords

emergency medicine, patient satisfaction, qualitative methods, transitions of care, pediatrics

Introduction

Improving care transitions for pediatric patients from the emergency department (ED) to home may improve patient and family experience, reduce unnecessary return visits, ensure families feel prepared to continue care at home, and lessen the socioeconomic burden of disease (1,2). Most young patients with acute febrile illnesses are discharged home, and communication about the medical and social aspects of disease occurs in a stressful and hurried interaction. The quality of verbal discharge communication has been shown to be highly variable (3). Therefore, written discharge instructions and educational material may be the only durable information from the visit.

Families present to EDs for myriad reasons to address burdens of disease (4,5). The most common reason is a perceived and urgent change in the severity of illness of the child (6–8). This includes both objective observations (fever, work of breathing) and parental worry, anxiety, and stress. These factors can influence healthcare utilization decisions and overall child health (9–12). Social factors contributing to the burden of disease are significant and disproportionally affect socioeconomically disadvantaged families (13).

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Efforts to improve discharge communication are heterogenous across illnesses and contexts. An implied assumption is that lack of parental knowledge about a disease process, which informs most interventions, may not be the most important contributor to poor outcomes (14). Addressing fear, worry and quality of life may be overlooked in written and verbal discharge education, contributing to further parental anxiety, worry and unnecessary return visits. The primary reason for return to ED is fear and uncertainty about disease progression, especially in young patients and those with detrimental social factors (15–17).

Therefore, including factors important to families in written discharge instructions for common ED conditions may improve the quality of communication in ways that are meaningful, address important non-medical needs, and optimize subsequent healthcare utilization decisions. However, the extent to which these domains are included in discharge instructions is unknown. The purpose of this study was to understand the content of discharge instructions and evaluate the extent to which comprehensive domains of disease are addressed.

Methods

Sampling Strategy and Data Collection

The instructions analyzed in this study were collected from a nationwide sample of pediatric EDs. A pool of nationwide respondents was selected to maximize variation in ED size, academic affiliation and geographic location. Respondents were solicited via email for the discharge instructions most commonly used in their institutions' EDs for influenza for young children. We also included a sample of discharge instructions for bronchiolitis, an alternative childhood illness for which parental stress and anxiety constitute a significant component of the burden of disease. No patient identifiers were collected. This project did not meet the Institutional Review Board's definition of human subjects research.

Approach and Data Analysis

Discharge instructions were categorized by ED size, location and academic affiliation. The Flesch-Kincaid Grade Level and the Flesch Reading Ease score were calculated using the average sentence length and the average syllables per word (18, 19). Content analysis was conducted using a multistep iterative process involving both independent and team work (20-22). First, we used clinical experience to create a list of expected codes and themes. All researchers then discussed codes using samples until we reached at least 90% agreement, refined and collated the codes into potential themes. Each handout was independently coded by two researchers, allowing for the formation of new codes and themes. Disagreements were resolved and data were organized in a master log. Themes were generated and checked in relation to the coded extracts and the entire data set (Supplement).

Results

We included 18 influenza and 9 bronchiolitis instructions in our final analysis. The average Flesch-Kincaid Grade level was 6.6 (3.9-9.3). 7 of 27 instructions were developed "in-house" by the institution, while 20 of 27 were adapted from commercially available sources, such as UpToDate. Instructions were analyzed from EDs with annual patient visits below 50,000 (28%), 50,000 to 100,000 (44%), and above 100,000 (28%). The average lengths of the influenza and bronchiolitis instructions were 3.1 and 2.7 pages, respectively. All analyzed instructed were printed on paper and given to families at the time of discharge. Instructions from two institutions includes areas for free text comments to be embedded in the disease-specific instructions. A minority included specific websites for further information and half of the instructions included a prominently displayed disclaimer that the information in the handout was not intended to replace advice from the healthcare clinician. Seven themes were generated from our analysis (Table 1).

Theme 1: General description of illness

This theme constituted the bulk of the first section of all the instructions, but various descriptions also occurred throughout the remainder of many of the instructions. Illness descriptions included information on the type of symptoms most children experience, including fever, chills, aches, cough and sore throat. Many compared these symptoms to common colds, but emphasized increased speed in onset and severity of symptoms. Nearly all samples described influenza as highly contagious. General examples of how transmission occurs were also part of this theme, setting the stage for informing parents about the nature of influenza.

Your child may have a fever, cough, and headache. Some kids also may have a sore throat, vomiting, diarrhea, runny nose, or sore muscles. They may feel very tired.

Most influenza instructions included the expected duration of the illness, while many also described how the severity of illness may vary between children and that some children may need to be hospitalized. Some discharge instructions highlighted that high fevers may not completely resolve throughout the course of illness, even with medications. *The fever associated with influenza may not go down to "normal" with medication: it may go down to 100-101.* This type of uncertainty was also included in descriptions about expected severity, although only five instructions include specific information about risk factors for worse disease in children.

The variability in diagnosis of influenza, both by clinical exam or laboratory testing, was notable in some instructions. Some discussed the inherent uncertainty in diagnosing young children with acute febrile illnesses.

| Themes | Description and codes |
|----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Illness description | A general description of a child's illness focusing on symptoms and duration of illness. <i>Codes</i> : fever; other symptoms; infection; contagiousness; diagnosis/test result; expected duration of illness; expected severity of illness; risk factors for severity of illness; long term problems |
| Cause of illness | A specific focus on pathogens that are likely to be responsible (or unlikely to be responsible) for a child's illness, as well as specific sites of infection (i.e., ears, throat, lungs). <i>Codes:</i> virus; bacteria; immune response; specific source of infection |
| Home care of child | Recommendations to caregivers around management of symptoms and support of the child through the illness period. <i>Codes:</i> hydration; comfort; prevent spread to others; home environment; bulb suction; nasal saline; smoke exposure; honey/lozenge; rest/sleep; nutrition |
| Medication instructions | Instructions to caregivers relating to medications, dosing, cautions and avoidances. <i>Codes:</i> medications to give; medication cautions; dosing; medications to avoid; antiviral medications; other |
| Getting help | Recommendations to caregivers about the importance of and when to follow up, including escalating follow up plans related to symptom severity. <i>Codes:</i> emergency follow up; urgent follow up; routine follow up; concerning signs/ symptoms; importance of follow up; caregiver knowledge of child's health/medications; other |
| Quality of life | Comments or mention of factors affecting patient or caregiver quality of life. <i>Codes</i> : daily activities; emotions; social life; perceived social support; reassurance; return to school/activities; overall quality of life |
| Internal consistency | Identified areas within the same discharge document where instructions can be misleading or conflicting. <i>Codes:</i> variable use of same words; conflicting advice |
| Health promotion | Instructions or guidance to caregivers about how to promote the child's and family's health status. <i>Codes</i> : avoid sick contacts; influenza virus vaccine; respiratory syncytial virus vaccine; car seat |

Table 1. List of Identified Themes, Their Descriptions, and Identified Codes.

Other infections may cause symptoms similar to the flu. So if healthcare providers need to be sure that someone has influenza, they might do a test.

The bronchiolitis instructions contained similar descriptions of symptoms and duration of illness. However, they did not emphasize contagiousness as much as the influenza instructions. Diagnostic procedures or viral testing for bronchiolitis were generally not described, and in one handout that did, specific reasons for *not* testing were made clear. One third of bronchiolitis instructions included information about potential long term complications (mainly wheezing) and detailed potential inpatient therapies.

Children who have trouble breathing or eating may need to stay in the hospital for 1 or more nights. They may receive intravenous fluids, oxygen or a breathing machine.

Theme 2: Pathophysiology and causes of illness

Distinct from the description of symptoms and course of illness, this theme emerged around the underlying cause and pathophysiology of disease. All of the influenza and bronchiolitis instructions clearly described that these illnesses were caused by viruses. This theme included some descriptions of epidemiology of yearly influenza, outlining reasons why some people may have recurrent illness.

Flu viruses change yearly, which is why people can get the flu every year and why the flu vaccine changes ear year. It spreads rapidly because the incubation period is only two days. After exposure, 20% of people come down with symptoms in four to six days. Additionally, fewer than half of instructions contained information detailing the differences between viral infections and bacterial infections. These instructions listed bacterial infections such as pneumonia and otitis media as potential complications for which antibiotics could be indicated.

Notably, bronchiolitis instructions contained significantly more description of the pathophysiology of disease. Nearly all these instructions contained descriptions of lung anatomy, inflammation, and mucus production. One handout contained a pictograph comparing healthy lung composition to the inflammation and obstruction occurring during bronchiolitis.

The virus can irritate tiny airways call bronchioles. The airway swell and fill with mucus, making kids wheeze.

Theme 3: Home care of the child

All instructions provided some advice to parents as to how to care for the child at home after discharge. The most common aspects of this theme were advice about hydration, humidified air, and prevention of disease spread to others. Multiple instructions included pictographs detailing methods to cover children's noses while sneezing, using elbow creases or tissues. This theme also included additional methods to care for children at home. Other methods include bulb suctioning and nasal saline usage for clearing nasal passages and encouraging rest for the child. Most instructions included brief general methods for suctioning the nose: "Use a bulb syringe to clear the mucus." A few included detailed instructions for how to suction effectively.

Put a couple drops of saline up one nostril and place large tube against baby's nostril (not inside) making a seal. (3-5 drops for babies less than 6 months; 10 drops for greater than 6 months). Use the mouthpiece to suck out mucous. Dump the mucous on the tissue. Repeat with the other nostril. Repeat process until clear.

In general, content related to this theme included brief, broad statements such as "Give plenty of clear liquids," and "Allow your child to rest." Home care instructions generally did not offer details about how to specifically prevent contagion, address coping with an ill child at home, or care measures for the caregiver or other members of the family.

Theme 4: Medication instructions and specific therapy

Medications to give febrile children were mentioned in nearly all of discharge instructions. These were generally mentioned by name, acetaminophen and ibuprofen, but specific dosing instructions were only provided in one third of instructions. Many specifically warned against aspirin use during febrile illnesses due to Reye syndrome risk. General cautions about other medications were less commonly described. In these cautions, parents were advised to "talk to your doctor" about any other medications to give during the illness. Antiviral medications were specifically discussed in three fourths of instructions.

You child has been prescribed oseltamivir. This is an antiviral medication. It is generally only given to higher risk children such as babies under two years old or children of any age with long term or complex medical conditions. It does not "cure" the flu but sometimes can help with the severity and duration of symptoms in higher risk children.

Most discharge instructions also specifically mentioned that antibiotics do not help with the flu and that they would only be prescribed if the child was found to have a co-infection. Nearly all bronchiolitis instructions also specifically mentioned that antibiotics are not helpful.

Theme 5: Getting medical help—what to watch for and what to do

As would be expected in discharge instructions, another theme provided guidance to parents regarding getting further help for a child's changing or worsening condition. A majority (but not all) of instructions included specific reasons to return to the ED or call a doctor immediately. These generally described trouble breathing, mental status changes, cyanosis, and excessive sleepiness.

Call your doctor now or seek immediate medical care if: Your child has a fever with a stiff neck or severe headache, is confused, does not know where he or she is, or is extremely sleepy or hard to wake up, has trouble breathing, breathes very fast, or coughs all the time, has a high fever, has signs of needing more fluids. Return to the ED for: bluish skin color, irritability, flu-like symptoms improve but then return with fever and worse cough, fever with a rash.

Notably, some descriptions of reasons to return immediately to the ED included fever, rash, and "looking sick," symptoms that parents could easily have come to the ED initially for and would not necessary immediately improve with therapy.

Other discharge instructions were more specific in descriptions of when to get help. While fever was frequently listed a reason to call a doctor during office hours, one handout mentioned, *There is NOT a particular temperature that is more worrisome than another. More important than the temperature is your child's behavior.* This more accurately qualifies for parents the expectations that fevers will continue during the illness. Most instructions described reasons for non-emergent follow up with a doctor, including prolonged fever or cough, new symptoms, worsening symptoms, or if the parent is concerned for any reason.

Fewer than one third of discharge instructions emphasized the general importance of follow up for the acute illness. Some strongly encouraged close parental communication with primary care after the visit. *Follow-up care is a key part of your child's treatment and safety. You are the most important factor in your child's recovery.* Others provided vague follow up recommendations or none at all.

Theme 6: Functioning at home, reassurance and quality of life

This theme emerged as many instructions offered insights into returning to normal life and reassurance about the disease. Many offered statements such as *Most of the time*, *the flu does not need any medicine other than acetaminophen*, and *Your child has no signs of a serious infection today*. A few instructions reminded parents about the importance of their own health and sleep to help their child. *Take care of yourself and the other people in your family*.

While nearly all instructions included guidance on when children should return to school or daycare, only half included any commentary on reassuring the caregivers or offering advice to improve quality of life. Some of this reassurance was indirect, focusing on the resilience of children. *The treatment of the flu depends on your child's main symptoms. It's no different from treating symptoms of the common cold.* Still others included reassuring statements tempered by warnings of progression of disease.

Most of the time, you can take care of your child at home. But if your child is not getting better or has a hard time breathing, he or she may need to be in the hospital.

Reassurance about the self-limited nature of disease was the most common type of comment related to family wellbeing and reducing anxiety. However, these statement were often directly followed by warning signs to watch for and reasons to return to the ED. No instructions included specific methods for caregivers and families to reduce stress at home, reduce anxiety, or improve sleep. No instructions mentioned ways to engage social networks, find assistance with household or social needs, or improve caregiver well-being during their child's illness.

Theme 7: General health promotion of patients and communities

The final theme in our analysis included general health promotion activities. This theme included descriptions of vulnerable populations and ways to prevent spread of disease. It also included general epidemiologic information about viral spread in the community and the importance of flu vaccinations for this community protection. This is distinct from physiologic descriptions of illness and preventing spread within the household. Two thirds of instructions included messaging about the importance of yearly flu vaccines to prevent spread in the community. One fourth included specific advice for parents to avoid contact of their sick child with elderly or chronically ill populations.

Discussion

This study is the first analysis of written discharge instructions commonly provided to families who present to pediatric EDs with acutely ill young children. Seven themes emerged from the analysis, primarily focusing on the physiologic aspects of disease, medication usage and guidance for further medical help. Advice and content on well-being, social aspects of disease, parental anxiety and reassurance were not well represented in the instructions.

Written discharge instructions represent a key aspect of education and communication between ED clinicians and families. Pediatric visits to EDs are usually for acute febrile and respiratory illnesses, and these visits generally require minimal specialized testing, imaging or therapy. While many of these complaints could be optimally managed in an outpatient medical home, many families choose to present to EDs for various reasons. Uncertainty, anxiety and worry can dominate this decision making for some families (23). If these aspects are not adequately addressed during the visit, suboptimal patient and family experiences, revisits and worse outcomes may result (8, 24). However, we found that the content of discharge instructions focused mainly on the physiology of disease processes. Little attention is given to social factors, parental well-being, anxiety or other non-physiologic aspects of disease. Careful consideration and study could determine if including these factors in discharge instructions could be one component of a multifactorial effort to improve family-centered emergency care to improve patient and family experience, revisits and outcomes (25, 26).

Prior work in asthma has shown some success in incorporating a patient-centered multifaceted approach to improving care transitions from acute care settings to home (27). These multifactorial interventions combine education, linkage with follow up, culturally appropriate action plans, and the provision of materials while in the ED. Careful culturally competent attention to patient and caregiver needs can influence design of these materials, such as improved asthma action plans, to increase parental self-efficacy, confidence and improve outcomes (28–30). Combined with quality improvement initiatives to increase guideline-adherent medical care, these patientcentered approaches have shown great promise to improve cost-effective asthma care for vulnerable families (31–33).

The study has demonstrated an opportunity to mirror this approach with family-centered design thinking in other common childhood diseases like influenza and bronchiolitis. Optimal discharge materials may need to strike a balance between addressing all components of disease important to families with the need to avoid information overload for families. Standardized verbal communication may also need to augment written discharge instruction to overcome literacy barriers. Future work should focus on understanding and addressing comprehensive aspects of disease using thoughtfully designed interventions to improve multifaceted outcomes during care transitions. Innovative solutions are needed to personalize the information included in discharge instructions to target domains most important to individual families. Our findings are an important foundational step in understanding the current status of written discharge instructions in the context of variability of parent/family perceptions of care, verbal communication and meeting family needs. Family input, continued iteration and redesign and balance of medical and social needs are important to improve the quality of the ED visit for the family to improve experience, reduce unnecessary return visits, and promote whole family health and well-being.

Limitations

This study has several limitations. Our sampling included discharge instructions only from pediatric EDs. While we were deliberate in collecting samples from a wide geographic area and from EDs of varying size, we did not include instructions from non-pediatric EDs. This limitation is blunted by the frequent use of commercially available instructions that are widely used in both pediatric and community EDs. We quickly reached thematic saturation in our samples. However, it is possible that themes in other ED settings may differ from our results.

It is also possible that other information that alters the main thematic elements of discharge communication would accompany the instructions we had available to analyze. Only pre-populated content was analyzed in this study and any personalized instructions that may have been added for specific families was not included. However, our sampling techniques were deliberately broad enough to attempt to include all written discharge instructions that may reasonably be expected to be given to each family with the illnesses of interest. While general clinical practice would likely include the instructions we analyzed, it is possible that we missed other written documents that may include substantial information for families. Similarly, we were unable to analyze any verbal discharge instructions communicated between providers, bedside staff, and families.

Conclusions

In this content analysis of discharge instructions provided to families who are discharged home after presenting to a pediatric ED for childhood influenza, we found physiologic aspects of disease were discussed in detail, but that other aspects important to families and caregivers were not well described. Further work is needed to determine if addressing these aspects, such as worry about progression of disease, impact on family well-being and contagiousness within the family, using multifaceted discharge communication techniques would be acceptable and helpful to families to improve familycentered emergency care for common childhood illnesses.

Authors' Note

This study did not include any patient information and was deemed by the Cincinnati Children's Hospital Institutional Review board as not human subjects research and did not require ethical approval.

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) received no financial support for the research, authorship and/or publication of this article.

Supplemental Material

Supplemental material for this article is available online.

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