



Parent Experiences Caring for a Child With Bronchiolitis: A Qualitative Study

Journal of Patient Experience
2020, Vol. 7(6) 1362-1368
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DOI: 10.1177/2374373520924526
journals.sagepub.com/home/jpx


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Abstract

Background: Bronchiolitis is an acute lower respiratory infection, with significant impacts on children and families and strains on the health care system. Understanding parents' experiences and information needs caring for a child with bronchiolitis is crucial to highlight misconceptions or issues contributing to the high burden. The objective of this qualitative study was to describe parents' experiences caring for a child with bronchiolitis. **Methods:** Qualitative description guided this study. Participants were recruited from the Stollery Children's Hospital emergency department (ED), a specialized pediatric ED in a major Canadian urban center. Semi-structured interviews were conducted with 15 parents. **Results:** Five major themes were identified: (a) their children's symptoms and behaviors, (b) bronchiolitis affects the entire family, (c) factors influencing parent's decision to go to ED, (d) ED experience for parents and their children, and (e) bronchiolitis treatment and management. Interviews revealed bronchiolitis has significant effects on both children and families and parents are generally unaware of bronchiolitis symptoms, treatment, and management. **Conclusions:** Our study highlights that parents have knowledge deficits when it comes to recognizing the presence and severity of bronchiolitis symptoms. Parents would benefit from having more evidence-based resources to enhance their knowledge about the nature of bronchiolitis.

Keywords

pediatrics, qualitative methods, bronchiolitis, parent experiences

Introduction

Bronchiolitis, often caused by respiratory syncytial virus (RSV) infection, is an acute lower respiratory infection, commonly affecting infants and children before age 2 years (1,2). While most children have only mild symptoms, some symptoms may progress, requiring intensive care (3).

Bronchiolitis treatment remains variable. Clinical practice guidelines, including the Canadian Pediatric Society (4) and the American Academy of Pediatrics (5) do not recommend chest radiography, corticosteroids, or bronchodilators and only suggest antibiotics for children with a bacterial coinfection (6). However, uptake of these guidelines is not widespread (4,6).

Bronchiolitis can have a significant impact on the health care system and children's health however, less is known about the distress experienced by parents and families (7). Parents may seek information on whether to seek medical attention (8), and while a wide range of information is available about bronchiolitis, parents may be unaware of where to find this information. Additionally, treatment variation for bronchiolitis may leave parents questioning what

information they can trust (9–11). Understanding parents' experiences and information needs caring for a child with bronchiolitis is crucial to highlight misconceptions, knowledge gaps, or systemic issues contributing to its high burden and is imperative in offering relevant information and education (12). The aim of this qualitative study was to describe parents' experiences caring for a child with bronchiolitis and identify their information needs managing bronchiolitis. The information needs identified by parents are reported elsewhere (13). Here, we explicitly report on the overall daily experience of parents caring for a child with acute bronchiolitis.

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Methods

Sample

Qualitative description guided this study (14,15). Participants were recruited by purposive sampling (16), at the Stollery Children's Hospital emergency department (ED). Participants were eligible if they were (a) a caregiver of a child 16 years old or younger; (b) presenting to the ED seeking care for their child with respiratory symptoms; and (c) fluent in English. In the ED, clinical team members identified eligible participants via the ED Information System and notified the Stollery research recruitment team so potential participants could be approached after triage in the ED waiting room. AC followed up with interested caregivers by telephone or email to schedule an interview once participants had been discharged home.

Data Collection

Data collection and analysis occurred concurrently until data saturation was achieved (16). Research assistants trained in qualitative data collection (AC, SLP) followed up with interested caregivers by telephone to schedule an interview at a mutually agreed upon date, time, and location or by telephone. Caregivers completed demographic information forms after consenting to participate. A semi-structured interview guide was used to capture caregiver experiences in relation to their child's bronchiolitis (see Supplemental Appendix). Interview questions moved from general to more specific with later interviews becoming more focused.

Data Analysis

Interviews were digitally recorded, transcribed verbatim and uploaded to NVivo 12 qualitative data management software (17). Data were analyzed thematically by a research assistant trained in qualitative data analysis (AC) and reviewed by the research team. No predetermined themes were created, rather attributes were derived from the data as the analysis progressed (18). Data analysis followed 4 steps. First, transcripts were read in detail several times. Second, AC conducted open coding of all transcripts and grouped codes into preliminary themes. Third, preliminary themes were grouped into a beginning organizational framework according to specific experiences. Field notes documented impressions and decisions. Rigor was enhanced through methods proposed by Morse (19) including thick description, and discussions among authors in which the coding framework, analytic procedures, preliminary findings, and interpretations were reviewed. Demographic data were analyzed descriptively.

Results

Fifteen (12 in-person, 3 telephone) interviews were completed with 15 (16 children) parents. Demographic characteristics of

Table 1s. Demographic Characteristics of Sample of Parents of Children With Bronchiolitis.

Variable	N (%)	
Gender		
Male	3*	20
Female	12*	80
Parents age		
Less than 20 years	1	6.7
20-30 years	1	6.7
31-40 years	12	80
41-50 years	1	6.7
Marital status		
Married/partnered	13	86.7
Single	2	13.3
Household income		
Less than \$25 000	1	6.7
\$25 000-\$49 999	1	6.7
\$50 000-\$74 999	3	20
\$75 000-\$99 999	1	6.7
\$100 000-\$149 999	4	26.7
\$150 000 and over	3	20
Prefer not to answer	2	13.3
Highest level of education		
High school diploma	2	13.3
Some postsecondary	2	13.3
Post-secondary certificate/diploma	3	20
Post-secondary degree	4	26.7
Graduate degree	3	20
Other	1	6.7
Number of children at home ^a		
1	4	26.7
2	7	46.7
3	3	20
4	1	6.7
Age of child brought to ED		
Less than 1 year old	10	62.5
1-2 years old	6	37.5
Frequency of bronchiolitis		
First episode	16	100

Abbreviation: ED, emergency department.

^aOne parent in our study had twins which accounts for the discrepancy in 16 children to 15 parents.

the parents and children are presented in Table 1. Five major themes emerged from our analysis.

Their Children's Symptoms and Behaviors

All children in our study could not verbalize feeling unwell, leaving parents to interpret the presence and severity of symptoms. Parents reported their child experiencing a loss of energy, appetite, and seeming generally uncomfortable. As one parent described,

“So first, they get a cold, runny nose, they're still pretty energetic. And the next thing you know—like the following day, they'll start a little cough. And then, I would notice a bit of wheezing coming in as well. He started getting more fussy, and restless.” (B-001).

The most common symptom reported was difficulty in breathing. For some children ($n = 9$), cough was present. Parents reported their child having “cold-like” symptoms such as a runny nose or fever. One parent said, “He had a cold, with so much mucous—he was so mucousy and it was hard to breathe.” (B-035). Another described their child’s symptoms as, “Shortness of breath. Nasal flaring. Runny nose. Ah, congested cough. She was just breathing at a rapid rate, probably 70 breaths a minute.” (B-028). One parent reported their child having such difficulty breathing their feet and hands turned blue,

“In the beginning, he was just sick. Like he had a fever. He wasn’t well. He had low appetite and he started to have a little wheezing and stuffed nose. Then the wheezing increased. He starts coughing a bit. In the end, when we came to Emergency, he already had some work of breathing—he became a little blue.” (B-042).

Blue limbs were only reported in one case, due to extremely low oxygen demands because of bronchiolitis. This case reflects a more severe (not typical) case of children.

Bronchiolitis Affects the Entire Family

Parents reported caring for a child with bronchiolitis caused emotional strain and impacts family life. One parent reported, “I feel helpless” (B-001). All parents were experiencing bronchiolitis for the first time, which elevated their fear and anxiety. One parent said, “Yeah. Of course, we feel nervous. Because it’s our first time to experience this, we don’t know what to do if the baby is having difficulty breathing.” (B-044). Parents reported feeling unprepared stating, “we weren’t prepared for how sick he would get.” (B-023).

Some parents ($n = 4$) were health care professionals (HCPs), but working in health care did not ease their fear and anxiety or prepare them for when their child became sick. One HCP parent stated, “Sometimes we think that we know what we’re doing, but it’s totally different when it’s your own child right?” (B-001). Parents reported losing sleep and combined with stress and worry sometimes resulted in tension in their family. As one parent stated, “Lack of sleep, honestly it was very stressful for both of us, obviously created some tension when you’re not sleeping.” (B-026).

Daily routines were disrupted, as parents typically had to take time away from work to care for their child. Children often had to miss child care to prevent passing on their symptoms. For children hospitalized, parents would often stay in hospital with them. For families with other children at home, this meant that while one parent was in hospital the other had to stay home from work with the other children. One parent said,

“We had to quit everything we were doing, ‘cause I was with him in the hospital for four days. And my husband was affected and my daughter as well. Like he had to drop everything he was doing to come help us.” (B-042).

Additionally, parents with other children reported feelings of guilt, as the sick child became the priority, often resulting in other children not getting the attention they desired. One parent said, “It was really difficult on him [other child] because he didn’t get to see us during that week.” (B-030).

Factors Influencing Parent’s Decision to Go to ED

Many parents’ decision to go to the ED was based on their child’s work of breathing. It was common for parents to wait 3 to 5 days before seeking emergency care when their child first began experiencing symptoms. However, as soon as their child’s breathing worsened, parents took them to the ED right away. One parent said, “With the breathing, for sure. He was working you know, a little bit more to breathe. And then, I noticed that he became kind of . . . he was restless, then he became kind of lethargic.” (B-001). Another parent said, “Yeah . . . we took them because their breathing was—it was apparent that they’re struggling to breathe.” (B-026).

Some parents decided to go to the ED due to persistent high fevers (>39.5 °C). One mother said, “His fever lasted for more than three days. I think it was the third day I took him in—and his cough was just super bad.” (B-005). Most parents described follow-up appointments with their pediatrician, but it was not common to take their child to see their pediatrician initially.

In Alberta, Alberta Health Services (AHS) Health Link provides a 24/7 telephone nurse advice and general health information service. Parents reported phoning AHS Health Link and taking their child to the ED based on the recommendation they received. One parent said, “We called our health link and they said to go to the hospital right now.” (B-026). In contrast, another said, “Yeah, I would definitely call health link if it was something different, but at that moment in time it was kind of like an emergency situation, so I didn’t.” (B-028).

Emergency Department Experience for Parents and Their Children

Parents reported having to wait hours (4-12 hours) in the ED before seeing a doctor. Others reported being assessed quickly (within 30 minutes). One parent said, “I was actually worried we were going to have to sit there for a while. But the nurse took me in right away, it was, I don’t know, less than 10 minutes.” (B-042). Another parent with sick twins said, “They got us in quickly when they realized the trouble the girls were having.” (B-026). Once assessed by a doctor, children were either sent home ($n = 4$), advised to wait in the

ED for at least 12 hours for further testing/monitoring ($n = 3$), or admitted to an inpatient medical unit ($n = 6$). One parent said, "He ended up having to be admitted overnight for low sats." (B-001). Another said, "They assessed and monitored them and didn't let them go until they were confident they were okay." (B-026). Two children were admitted to the intensive care unit for 3 days, followed by 2 days on an inpatient medical unit. This occurred in 2 cases due to severity of the episodes.

Children sent home after assessment were advised to monitor symptoms or were prescribed medications, such as bronchodilators (eg, Ventolin inhaler). Others were given oral steroids like, dexamethasone. One parent, sent home without medication said, "They [physician] just asked us to get some Tylenol." (B-035). Some children were prescribed antibiotics like, amoxicillin. Parents stated antibiotics were prescribed as a precautionary medication where a bacterial infection, such as pneumonia, was suspected. One parent stated, "They asked me to use the antibiotic until they got the results [lab results]" (B-040). Some parents who were sent home, came back to the ED for reassessment as they felt symptoms were worsening or not improving ($n = 5$).

Children were advised to wait in the ED for further testing or monitoring to rule out other problems (eg, pneumonia) or to assess how the child responded to treatments (eg, nebulized medications). One parent said, "They did the urine, the blood tests, and the x-ray to make sure that it wasn't anything like pneumonia." (B-005). Another parent said, "They were just watching her. They waited to see if after they gave her that mask [nebulizer] if she'd pick up a bit" (B-043). The most common reasons for children being admitted to an inpatient medical unit was low oxygen saturations on room air ($<90\%$) indicating the child required oxygen therapy.

The tests and procedures performed in the ED varied. Many children received a diagnosis of bronchiolitis based on low oxygen saturations ($<90\%$) on room air. Another common test performed was a nasal swab, where a mucous sample was obtained from the child's nose and sent for testing. Some parents reported their child having chest X-rays or blood work. Other procedures, such as urine tests, were not typically performed or only performed to rule out other potential problems. Parents reported their children being irritable, often accompanied by inconsolable crying during tests and procedures, making for a traumatic experience. One parent said,

"He didn't like the hospital for sure. He hated it, actually. And when they had put the nasal prongs in he just—he was trying to rip it out of his nose. So yeah, he didn't sleep much at all." (B-001).

Additionally, parents reported the ED experience as traumatic for themselves, having to experience their child upset and uncomfortable. Despite the trauma parents experienced, the majority of parents stated understanding why these procedures were done.

Bronchiolitis Treatment and Management in ED

Children were placed on pulse oximetry in the ED (measured blood oxygen saturation). If low ($<90\%$), children were placed on oxygen therapy. Two children, with severe bronchiolitis, were placed on an Optiflow machine which administers warm and humidified high-flow oxygen via nasal cannula. Suctioning of the nose due to excessive mucus production was performed on most children. One parent said, "Yeah, every hour we needed to call the nurse for them to suction his nose." (B-044). Some children received bronchodilators (ie, Ventolin) and/or corticosteroids (ie, dexamethasone). Children who were eating and drinking less, received rehydration therapy. Once children were able to maintain adequate oxygen saturations (without oxygen therapy), they were sent home. A few children were sent home with inhalers (ie, Ventolin, Q-Var), but the majority of children were sent home with instructions to monitor symptoms and make a follow-up appointment with their pediatrician in 1 to 2 weeks.

More than half of parents indicated not receiving education about bronchiolitis. During their time in the ED, one parent said,

"People were kind of like staring—outside of our room. And there's a crowd of doctors and nurses, but nobody was really communicating to us what was going on. So that was hairy, 'cause we could tell that they were concerned or that they were watching him, but they wouldn't communicate to us." (B-023).

Of the parents who did receive education, 4 received verbal education, and 2 indicated only receiving this education because they asked questions. Three parents received written information they could refer to after leaving the ED. Whether parents actually referred to these resources upon discharge is unknown.

Discussion

This study provides detailed perspectives on parents' experiences caring for a child with bronchiolitis. These findings add to existing literature exploring parent experiences with children during acute pediatric illnesses and provide valuable information for HCPs and researchers aiming to improve these experiences for parents. Our findings suggest that parents, especially those experiencing bronchiolitis for the first time, are fearful for their child's life, feel anxious and unprepared, and require information from HCPs about bronchiolitis. We have organized our discussion in relation to our key study findings (a) their child's symptoms and behaviors, (b) bronchiolitis affects the entire family, and (c) ED experience for parents and children.

Their Child's Symptoms and Behaviors

Parents described common bronchiolitis symptoms, including difficulty breathing, excess mucous production and

increased irritability. While these symptoms are common, parents admitted not knowing these symptoms were indicative of bronchiolitis. This finding is congruent with other qualitative work, where parents regarded these symptoms as unusual and worrisome, but were unable to recognize them being related to RSV, or when to go to the ED (20,21).

Bronchiolitis Affects The Entire Family

Our findings suggest bronchiolitis causes emotional strain for parents and disruptions of daily routines. These findings are similar to another study by Leidy et al (7) reporting parents of RSV-infected children show anxiety levels similar to those of mothers with premature infants in the neonatal intensive care unit. Leader et al (22) found that infants hospitalized for RSV infections results in numerous time, productivity, and out-of-pocket losses for parents. This study found the average time burden associated with an RSV hospital admission for full-term infants was 3 to 4 days and increased for premature infants (5-6 days). These time losses are slightly higher compared to children in our study. However, children less than 1 year, premature infants, or those considered to have severe RSV infections had longer admissions.

All parents experienced bronchiolitis for the first time, causing feelings of worry and unpreparedness, as they had no experience against which to judge the illness (23). Similarly, Peeler et al (20) found mothers expressed intense fear when their child was diagnosed with bronchiolitis due to feeling unprepared and not understanding what was happening or going to happen to their child. Through discussion with parents, it is clear that bronchiolitis can be as distressing for them as for children.

Bronchiolitis negatively impacts quality of life for families. Lack of sleep, worry, feeling helpless, and having to alter daily schedules are most affected. Lapillonne et al (24) found similar results. This study, and others, found the emotional impacts and alteration to daily schedules persists several weeks after hospital discharge (7,24).

Emergency Department Experience for Parents and Children

The ED experience for parents and children in our study mirror the published literature on practice variation for bronchiolitis (25,26). While some parents received care in accordance to current practice guidelines, others did not. It is recognized that the decision to hospitalize a child with bronchiolitis is a complex process impacted by the course of the illness and other clinical, social, and resource factors. However, lack of standardization in treatment can result in unwarranted care and economic and resource strain to the health care system (26). A large international study on practice variations in acute bronchiolitis revealed more than 30% of infants hospitalized for bronchiolitis did not receive any evidence-based supportive therapies. Not only does this

practice variation occur between hospitals and facilities but within hospitals among different physicians (25). This may explain why some parents who made multiple trips to the ED received different care each time.

Parents feared for their child when they had bronchiolitis. Similar to the study by Peeler et al (20), parents felt they were unable to control the situation; they felt fearful and helpless and questioned their parenting skills. Parents described procedures performed on the child such as X-rays, nasal suctioning, and oxygen therapy as traumatic to witness. Leidy et al (7) also found caregivers described the procedures performed on children to be among the most stressful aspects of their experience with bronchiolitis.

Supportive care is the cornerstone of treatment for bronchiolitis. The main management goals are to ensure adequate oxygenation and hydration. Supplemental oxygen is not recommended unless oxygen saturations persist below 90%. Limited suctioning to clear the nares is also recommended, as there is insufficient evidence to support its use. (25,27). Children were commonly treated with bronchodilators and oxygen therapy, viral studies, and X-rays in the ED. These treatments place significant burden on the child and family, in addition to increasing health care costs. Furthermore, despite the implementation of treatments such as bronchodilators, X-ray, or viral studies, these treatments and investigations may potentially add little in managing bronchiolitis (28). In fact, bottom-line recommendations indicate that routine laboratory tests and chest X-rays are not helpful in diagnosing or managing bronchiolitis and chest X-rays are associated with increased use of antibiotics, which are also not a recommended treatment (27). The variation in treatment practices further highlights a need for improved knowledge translation (KT) processes among HCPs that will allow recommendations to be disseminated widely.

Limitations

Interviews were conducted at a single point in time and only with parents seeking care in the ED. We relied on parent self-report of their experience, and recall bias is possible. It is important to note that all parents reported their child experiencing bronchiolitis for the first time. Thus, the emotional experience as described by parents may be heightened. Despite extensive efforts to ensure variation in parent demographics, our participants consistently possessed high levels of education.

Conclusion

Our findings reinforce and adds to existing literature on parents' experiences caring for a child with bronchiolitis, indicating that bronchiolitis has significant negative effects on children and families (7,9, 20,21). Our findings highlight that bronchiolitis affects the entire family; parents are anxious and fearful for their child and have knowledge deficits when it comes to recognizing the presence and severity of

bronchiolitis symptoms. Parents would benefit from having more evidence-based resources to enhance their knowledge.

Practice Implications

Findings from this study and our study exploring parents' information needs and preferences related to bronchiolitis (13) will inform the development of digital KT tools for parents of children with bronchiolitis. Parent experiences will be used to create a narrative for the digital KT tool. Providing timely, appropriate, and engaging research-based information to families about bronchiolitis may enhance their ability to communicate with HCPs about their questions, concerns, and expectations for care and may increase their confidence to actively participate in health care decision-making for their child.


Declaration of Conflicting Interests

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

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Shannon D Scott's research is supported by a Canada Research Chair for Knowledge Translation in Child Health and a Distinguished Research award from the Stollery Children's Hospital Foundation. Lisa Hartling is supported by a Canada Research Chair for Knowledge Synthesis and Translation and is a Distinguished Researcher with the Stollery Science Lab supported by the Stollery Children's Hospital Foundation. This project was supported by research funded by the Networks of Centres of Excellence (Knowledge Mobilization Initiative), with matching dollars from the Women and Children's Health Research Institute (partnership funding).

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Supplemental Material

Supplemental material for this article is available online.

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Author Biographies

Alyson Campbell is a PhD candidate (Faculty of Nursing) at the University of Alberta. Alyson's research interests span both child health and knowledge translation (KT). Specifically, her doctoral

work is in the area of pediatric concussion. Her research involves a multi-phase, multi-methods study, focusing on the development and dissemination of an innovative KT tool about pediatric concussion for parents and children.

Hartling is a professor in the Department of Pediatrics at the University of Alberta. Dr Hartling is a Canada Research Chair (Tier 1) in Knowledge Synthesis and Translation, and a Distinguished Researcher with the Stollery Children's Hospital Foundation. She holds several leadership positions including Director of the Alberta Research Centre for Health Evidence. The focus of Dr. Hartling's work is to gather and synthesize the best available scientific evidence to help support decision-making by healthcare providers, administrators, and patients and their families.

Samantha Louie-Poon is a PhD student (nursing) at the University of Alberta. Samantha is interested in bridging concepts of health equity and social justice into knowledge translation approaches. Through her research, Samantha seeks to improve the health outcomes of migrant children resettled in Canada by examining the existing climate of health information delivery. Specifically, Samantha's research aims to develop health information that appropriately navigates cultural nuances, intersectional needs, and positional power.

Shannon D Scott is a professor in the Faculty of Nursing at the University of Alberta. She currently holds a Canada Research Chair for Knowledge Translation in Child Health and a Stollery Distinguished Researcher Award. Shannon's research program, Translating Evidence in Child Health to enhance Outcomes (or ECHO), aims to improve the health outcomes of children in Alberta and Canada through application of the best research evidence, as well as exploring factors that shape research implementation.