



**Parent information needs and preferences related to
pediatric bronchiolitis: a qualitative study**

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Keywords:	Pediatrics, Qualitative research, Knowledge translation, Patient Oriented Research
Abstract:	<p>Background: Bronchiolitis, an acute lower respiratory tract infection, affects more than one third of children before the age of two. Bronchiolitis has the potential to severely affect a young child's health and cause significant anxiety for parents. The anxiety parents experience often leads them to seek emergency or other medical care to manage their child's illness. While a wide variety of information is available, parents are not always aware of this material, and if they are, the treatment variability for bronchiolitis can leave parents uncertain about what to do. The aim of this qualitative study was to explore parent experiences and information needs caring for a child with bronchiolitis.</p> <p>Methods: This study used a qualitative descriptive approach. Participants were recruited by purposive sampling from the Stollery Children's Hospital emergency department (ED), a specialized pediatric ED in a major Canadian urban center (Edmonton, Alberta). Individual semi-structured interviews were conducted with 15 parents.</p> <p>Results: Three major themes were identified: 1) parent information needs about bronchiolitis, 2) parent preferred information sources, and 3) parent preferred information delivery formats. Findings indicate that parents want and require credible, and easy to understand information about bronchiolitis in a variety of formats, and especially value information directly from a healthcare professional or an evidence-based internet website.</p> <p>Interpretation: This study provides important information about parents' information needs for bronchiolitis in children. Identifying the information parents want and value in relation to acute pediatric illnesses is imperative to developing innovative educational approaches for parents that reflect patient-centered care.</p>

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Manuscript: Parents information needs and preferences related to bronchiolitis: a qualitative study

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 3
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Title Page
3. Occupation	What was their occupation at the time of the study?	Title Page and page 3
4. Gender	Was the researcher male or female?	All female (as per authors listed on title page)
5. Experience and training	What experience or training did the researcher have?	Page 3 (research assistants, registered nurses)
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Page 3
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 3
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pages 3-4

Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pages 2-3
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 3
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 3
12. Sample size	How many participants were in the study?	Page 3 and Table 1
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Pages 3-4
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 3
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Page 3
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 3 and Table 1
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 3 and Interview Guide (additional file)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 3
20. Field notes	Were field notes made during and/or after the inter view or focus group?	Pages 3-4
21. Duration	What was the duration of the inter views	Page 3

	or focus group?	
22. Data saturation	Was data saturation discussed?	Page 3
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Pages 3-4
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 3-4 (coding sequence)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 3-4
27. Software	What software, if applicable, was used to manage the data?	Page 3
28. Participant checking	Did participants provide feedback on the findings?	N/A
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 2
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Table 2 and pages 4-7
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pages 4-7
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pages 4-7

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3 **Title: Parent information needs and preferences related to pediatric bronchiolitis: a qualitative study.**
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INTRODUCTION

Bronchiolitis, an acute lower respiratory tract infection, affects more than one third of children below age two and is the most common cause for hospital admission in their first year (1). Respiratory syncytial virus (RSV) is the most common cause of bronchiolitis and is characterized by inflammation and edema in the small airways with increased mucous production (2). While most instances of bronchiolitis are self-limiting, the disease can result in severe complications, such as pneumonia and empyema. These complications can severely affect a child's health, and may result in hospitalization (3). While bronchiolitis can clearly have an impact on the physical health of children, studies indicate that parents suffer psychologically and emotionally through their child's illness and need support (4, 5).

Parental anxiety and uncertainty are common during a child's illness, leading them to seek emergency or medical care (6). A wide variety of parental information is available including written and online material. Parents are not always aware of this material, and if they are, the clinical treatment variability for bronchiolitis can leave parents uncertain about who or what sources of information they can trust (3, 6, 7). It is therefore imperative to understand the information needs of parents in relation to bronchiolitis, understand where they look for this information and how they prefer this information be provided. The aim of this qualitative study was to explore parent experiences and information needs caring for a child with bronchiolitis. Here, we report explicitly on the information needs and preferences of parents.

METHODS

This exploratory study used qualitative descriptive approaches (8). Ethics approval for this study was obtained from the University of Alberta Health Research Ethics Board and institutional approval was obtained from Alberta Health Services prior to participant recruitment.

Sample

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3 Participants were recruited using purposive sampling from the Stollery Children’s Hospital
4 emergency department (ED), a specialized pediatric ED in a major Canadian urban center. The inclusion
5 criteria for study participation were 1) caregiver presenting to the Stollery Children’s Hospital ED seeking
6 care for their child with bronchiolitis symptoms; 2) caregiver is fluent in English; and 3) caregiver agrees
7 to be contacted by the research team for one-on-one interview. Recruitment team members identified
8 eligible participants via the ED Information System. Data collection and analysis occurred concurrently
9 over an 8-month period until data saturation was achieved (9).

19 **Data Collection**

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22 Caregivers completed demographic information forms after agreeing to participate. The first or
23 third author (registered nurses and research assistants) conducted 15 semi-structured interviews.
24 Interviews were conducted in person at a mutually agreed upon date, time and location or by
25 telephone. All interviews were digitally recorded and transcribed verbatim. Interview questions moved
26 from general to specific with later interviews becoming more focused (See Interview Guide,
27 Supplementary Material).

36 **Data Analysis**

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39 Inductive thematic approaches guided analysis. NVivo 11 was used for data management. First,
40 transcripts were read in detail several times. Second, the first author conducted open coding of all
41 transcripts and grouped codes into preliminary categories. Third, preliminary categories across cases
42 were grouped into a beginning organizational framework according to explicit information needs.
43 Credibility or trustworthiness of the data was guided by four criteria: 1) credibility, 2) confirmability, 3)
44 dependability, and 4) transferability. Credibility was addressed by obtaining a broad sample, allowing for
45 multiple and diverse perspectives and reducing the risk of bias from a particular participant
46 demographic (i.e. all females, high-income). We addressed confirmability by maintaining a
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3 comprehensive audit trail, field notes, memos and interview tapes. Dependability was addressed by
4 keeping a detailed audit trail documenting all decisions made throughout the research process. Finally,
5 transferability was addressed through thick descriptions and further enhanced through purposive
6 sampling techniques. Analytic rigor was enhanced through author discussions in which the coding
7 framework, analytic procedures, preliminary findings and interpretations were reviewed. Demographic
8 data were analyzed descriptively.
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16 17 **RESULTS**

18 19 **Demographics**

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23 Demographic characteristics of participants are presented in **Table 1**. The mean age of children
24 was 9 months ($SD=7.06$) and all of these children ($n=15$, 100%) experienced bronchiolitis for the first
25 time. We explored three major recurrent themes: 1) parents' information needs about childhood
26 bronchiolitis, 2) parents' preferred sources to seek health information about their child and 3) parents'
27 preferred formats to receive health information regarding their child. Each of these themes contains a
28 number of subthemes. Participant quotations supporting each theme are displayed in **Table 2**.
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37 **Theme 1: Parents' information needs about childhood bronchiolitis**

38 39 ***Subtheme 1: Recognizing Severity***

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43 Parents had difficulty interpreting the meaning and severity of bronchiolitis symptoms. All
44 children in our study were experiencing bronchiolitis for the first time, and parents commonly reported
45 feeling unprepared and not knowing what to expect. Recognizing symptoms, symptom severity, and
46 when to go to the ED were interpreted as fundamental information needs, and without this knowledge,
47 parents' abilities to manage their child's illness and seek timely medical care was hindered. Recognizing
48 symptoms and determining when to seek emergency care improved with experience for some, but not
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3 all, parents (i.e. experience of bronchiolitis with a different child). Overall, first time experiences often
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5 resulted in the child's symptoms exacerbating and not receiving timely medical attention. Seven children
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7 were admitted to hospital for 24 hours or more, including two children who were admitted to the
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9 pediatric intensive care unit. Eleven children required oxygen. Six parents reported the number one
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11 thing they would have done differently to help their child was not to wait as long before seeking
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13 emergency care.
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16 17 ***Subtheme 2: Knowing "About" Bronchiolitis*** 18

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20 Parents identified wanting to know more about what causes bronchiolitis, what the treatments
21
22 are, and if or how bronchiolitis can be prevented. Most parents reported receiving little to no
23
24 information about bronchiolitis from their health care providers (HCPs) from the time of diagnosis to the
25
26 time of discharge. Many parents disclosed looking for information online, but preferred to learn this
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28 information from a HCP.
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31 32 **Theme 2: Parents' preferred sources to seek health information about their child** 33

34 35 ***Subtheme 1: Talking to a Health Care Professional*** 36

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38 Parents commonly reported turning to a HCP, typically their pediatrician, when their child
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40 became ill. Parents reported calling their pediatrician first, to seek professional opinion, before going to
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42 the ED. Some parents reported going to the ED was a decision made by their pediatrician. Parents
43
44 trusted their pediatrician and receiving information from the pediatrician often relieved parents'
45
46 anxiety. However, few parents reported actually receiving an adequate explanation of bronchiolitis.
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48 When asked what information they received from HCP's about bronchiolitis common responses were
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50 "not much" and "yeah, nothing". In the province of Alberta, Alberta Health Services (AHS) Health Link
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52 provides a 24/7 telephone nurse advice and general health information service. Parents reported
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54 phoning AHS Health Link when they were uncertain if their child needed to be seen by a physician (n=6).
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Subtheme 2: Internet

In addition to seeking information from HCPs, many parents (n=12) turned to the Internet to learn about bronchiolitis. Parents commonly used Internet search engines (i.e., Google) to look up their child's symptoms (e.g. runny nose, fever, cough) before going to the ED, as many did not know to specifically search for "bronchiolitis". Upon discharge, parents searched "bronchiolitis" to find out additional information such as signs and symptoms, treatments, and prevention. When asked how parents determined what Internet sources they could trust, they distinguished between "clinical" versus "opinion" websites. Parents felt they could trust "clinically based" (i.e., WebMD) more than "opinion" (i.e., social media, blogs) websites. Most parents reported against using social media to seek health information. Parents preferred Internet sources that provided information in "layman's terms" and were Canadian-based.

Theme 3: Parents' preferred formats to receive health information regarding their child

Subtheme 1: Written Information

Parents preferred receiving information about bronchiolitis in written forms, such as pamphlets or information sheets (n=6). Parents indicated that a pamphlet with information outlining what bronchiolitis is, common symptoms, and when to go to the ED would be useful. Parents reported receiving these pamphlets before their child becomes sick would be beneficial, such as in their pediatrician's office during regular check-ups, vaccination clinics or as part of a newborn discharge package. Parents indicated knowing about bronchiolitis before it happens would better prepare them for the experience.

Subtheme 2: Online sources

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3 Despite parents indicating the Internet can have untrustworthy information sources, many still
4 chose to look up information online. Parents most commonly looked to medical websites that provided
5 information in a simple way that they could scroll through and read. When asked about videos as a way
6 to deliver information, some parents indicated they would not be inclined to watch, while others felt
7 videos could be useful to learn about things like proper techniques for suctioning with bulb suction.
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14 ***Subtheme 3: Verbal Communication***

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16 Overall, parents preferred to receive information in person, especially if coming directly from a
17 HCP. Parents described how talking to friends and family often helped them through their experience
18 with their child's illness. Receiving face-to-face confirmations and reassurances about their child's illness
19 and treatment plan relieved anxiety.
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27 **INTERPRETATION**

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30 Bronchiolitis is common in young children and causes substantial parental concern. Our study
31 provides a comprehensive perspective on caregivers' information needs related to their child's
32 bronchiolitis, reinforcing and adding to existing literature on childhood bronchiolitis. Our findings build
33 upon a mixed-methods systematic review conducted by our research team on the experiences and
34 information needs of parents related to bronchiolitis. This systematic review found that parents need
35 information about bronchiolitis, but limited research is available to inform the type, timing, and source
36 of information parents would find most useful (10). Findings from this study address these limitations.
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38 We have organized our discussion by our key study findings 1) parents' information needs about
39 childhood bronchiolitis, 2) parents' preferred sources to seek health information about their child and 3)
40 parents' preferred formats to receive health information regarding their child.
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53 ***Parents' Information Needs about Childhood Bronchiolitis***

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3 Parents' information deficits were evident in their comments (i.e., what causes bronchiolitis?
4 How can I prevent my children from getting bronchiolitis?) and the self-reported frequency of ED visits.
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6 All 15 parents reported taking their child to the ED 1-5 times. Parents felt they received insufficient
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8 information on how to recognize symptom severity, especially experiencing bronchiolitis with their child
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10 for the first time. Parents often overlooked symptoms of bronchiolitis such as rapid breathing and in-
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12 drawing until an emergency occurred. Our mixed-methods review found that parents often have
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14 difficulty assessing the seriousness of respiratory tract infections (10). Similarly, in previous qualitative
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16 work by Peeler et al (11) parents found they could tell their child was sick, but could not always identify
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18 signs specific to bronchiolitis. Yael et al (12) reported parents sometimes felt unaware of what
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20 symptoms might warrant further medical care. Inaccurately estimating the severity of bronchiolitis may
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22 lead to missed opportunities for timely treatment, resulting in a significant threat to a child's well-being.
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24 In our study, 7 of 15 children were admitted to hospital for at least 24 hours, with two of these children
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26 requiring intensive care.
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33 Parents in our study suggested receiving educational information about bronchiolitis before
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35 their child got sick might have been helpful. This is congruent with findings from Neill et al (13)
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37 suggesting that educational material assessing illness severity may be effective in supporting parents to
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39 care for their children and only seek help when necessary. Working with parents to promote an
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41 understanding on how to accurately interpret bronchiolitis symptoms may promote parent confidence
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43 while reducing anxiety and unnecessary ED visits.
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47 ***Parents' Preferred Sources to Seek Health Information about their Child***

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50 Our findings identified parents prefer to receive information from a trusted HCP when they have
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52 a sick child. Trusted HCPs included their pediatrician, family physician or nurses. This finding is
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54 congruent with other research that has examined where parents prefer to look for health information
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3 for pediatric conditions such as RSV, otitis media and gastroenteritis (14-17). Further, as Jones et al (18)
4 highlighted, for worried parents nothing will replace face-to-face reassurance from a HCP. Although
5 parents in our study value and prefer to receive information from a HCP, few parents reported receiving
6 adequate explanations on the nature of bronchiolitis, treatment options or illness trajectory. This finding
7 is consistent with other qualitative studies reporting that mothers described not being informed about
8 how their child's illness would progress and what the prognosis would be (11). Similarly, Cabral et al (19)
9 found that parents can find it difficult to understand acute illnesses in their child and feel disempowered
10 by inadequate information sharing by doctors. Our study, and others, (11, 18, 19) suggest missed
11 opportunities occur to inform parents about the appropriate care and management of respiratory tract
12 infections.
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26 Parents from our study indicated that receiving timely information verbally, written or from an
27 online credible website would be helpful and preferred. This is consistent with research indicating the
28 receipt of timely information about a child's illness can help alleviate parental fears and help establish
29 trusting relationships with HCPs (11). It is therefore critical to develop appropriate and accessible
30 information to share with parents.
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38 ***Parents' Preferred Formats to Receive Health Information about Their Child***

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41 Although parents may seek information from a variety of sources to learn about their child's
42 bronchiolitis, these may not always be reputable (3). Parents in our study reported turning to the
43 Internet for treatments and symptoms of bronchiolitis, despite recognizing Internet sources cannot
44 always be trusted. Parental need for high-quality Internet-based resources is not surprising given the
45 evidence that parents are increasingly using the Internet to access health information. A survey of 360
46 parents found 52% sought health information for their children on the Internet (20, 21). Providing
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3 parents with accessible information online that is credible, is essential to ensuring they are making well-
4 informed decisions about their child's health.
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8 Limitations of this study include interviews conducted at a single point in time and only with parents
9 who were seeking care in the ED. Recall bias may be present as we relied on parent self-report of their
10 information needs. Caution should be used when generalizing the results of this study to other regions,
11 populations, and child health conditions. Participants reported high levels of income and education and
12 were recruited in the ED of a tertiary care facility in an urban area in a developed country; thus, findings
13 cannot be extrapolated to caregivers that manage bronchiolitis at home without seeking emergency
14 care, or caregivers in other types of care centers or geographic regions.
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24 **Conclusions**

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27 These findings are valuable and necessary to develop information resources about bronchiolitis
28 that parents will find useful and relevant. Involving parents in the development of information resources
29 about acute pediatric illnesses, like bronchiolitis, supports the general trend towards involving patients
30 in research, emphasizing the importance of working collaboratively with end-users of interventions (13).
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37 It is recognized that one approach to deliver information to parents about childhood
38 bronchiolitis will not be appropriate for everyone and a variety of techniques and resources are
39 required. However, the results of our study reveal that generally parents prefer to seek health
40 information directly from a HCP, or online. Parents value information that is easy to understand and
41 considered credible.
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Table 1. 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 post-secondary	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		
• 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	9	60
• 1-2 years old	6	40
Frequency of Bronchiolitis		
• First episode	15	100

Table 2: Participant quotes to support thematic analysis

Thematic analysis	Participant quotes
<p>Theme 1: Parents' information needs about childhood bronchiolitis</p> <p><i>Subtheme 1: Recognizing Severity</i></p>	<p><i>"I didn't really know that a virus could make my daughter have that much trouble breathing"</i> (Interview 3, child age 1 year)</p> <p><i>"like, I always knew they were gonna get sick, but I always thought it would be like a one or two day thing"</i> (Interview 5, child age 6.5 months)</p> <p><i>"it was a little difficult to get at which point he actually has to go to Emergency"</i> (Interview 10, child age 6 weeks)</p> <p><i>"for a parent who doesn't have a medical background, it is very hard to understand that point, where you have to go right away to Emerg"</i> (Interview 11, child age 7 months)</p> <p><i>"I think we—we waited longer [to go to the ED] because we thought maybe it was something to recover from quickly"</i> (Interview 5, child age 6.5 months)</p> <p><i>"Well, he's our third child, so we've got two kids before, right? So normally—when the kids get sick, we give them Tylenol, something like that, but when we notice they start to get difficulty breathing, then we know we gotta go to the doctor"</i> (Interview 6, child age 19 months)</p> <p><i>"It's not like, "Oh yeah, I've done this before...it's like oh my god, what do I do again? Like this is happening again? What did I do the first time? I don't remember"</i> (Interview 1, child age 11 months)</p>
<p><i>Subtheme 2: Knowing "About" Bronchiolitis</i></p>	<p><i>"I didn't know a whole lot about it [bronchiolitis]"</i> (Interview 9, child age 2 years)</p> <p><i>"I was asking that, how it has been caused? And...why-what is the source of these symptoms?"</i> (Interview 1, child age 11 months)</p> <p><i>"they [healthcare team] didn't really explain like how-or what kind of symptoms I should be looking for"</i> (Interview 1, child age 11 months)</p>

	<p><i>“To be honest, like I had Googled it a bit. So, I knew to look for in drawing and stuff. Nobody had really told me that” (Interview 13, child age 7 months).</i></p>
<p>Theme 2: Parents’ preferred sources to seek health information about their child <i>Subtheme 1: Talking to a Health Care Professional</i></p>	<p><i>“I’ll just call the pediatrician and just take an appointment...at some point, it’s just saying well, I’m gunna try to rely on somebody who’s more knowledgeable than me for this specific problem” (Interview 3, child age 14 months).</i></p> <p><i>“So, I called the doctor – we had gone already a couple of times to the doctor. But I called and I just said that he wasn’t getting better, and I asked if I should bring him back in. This was about five days after – or six days after he originally got sick. And then, when we went into our pediatrician’s office, he rushed us for a chest x-ray and some blood work, and then back to his clinic and by the time we had got back to his clinic, he had read the chest x-ray report. He then contacted EMS to take us to the Stollery” (Interview 4, child age 16 months)</i></p> <p><i>“As much as we wanted to go home, it was really good that he [pediatrician] had him admitted. Because you know, that kind of really alleviated any fears that were left in me, because I knew, you know, he was being looked after by medical professionals”. (Interview 1, child age 11 months)</i></p> <p><i>“So I was calling Health Link, just-you know cause it’s always...it’s totally helpful to talk to somebody” (Interview 11, child age 7 months)</i></p> <p><i>“Normally when they get sick, we call the Health Link line. That—it’s our number one” (Interview 6, child age 19 months).</i></p>
<p><i>Subtheme 2: Internet</i></p>	<p><i>“Google is like a mom’s...best friend,” (Interview 1, child age 11 months)</i></p> <p><i>“yeah, I Googled like...worsening coughs, and like fever lasting longer than three days” (Interview 2, child age 3 months)</i></p> <p><i>“If I see like symptoms that seems to me, strange, other than being a normal cold, then, yes. I check online” (Interview 14, child age 1 year)</i></p>

	<p><i>“Like I’ll look at like the Mayo Clinic, or...ones that I know are actually from the health care field and not just somebody’s experience,”</i> said one parent (Interview 12, child age 5 months).</p> <p><i>“You know, like a clinical, kind of, status or whatever. The website—like Web MD is a good site—for me anyway”</i> (Interview 1, child age 11 months).</p> <p><i>“I am a part of...well, the parent groups [on social media] but I don’t ask for...health information through those”</i> (Interview 13, child age 2 months)</p> <p><i>“There’s some [websites] that are meant for...for parents to just kinda, you know, summarize...in layman’s terms, pretty much. You know, symptoms to look for, and what you need to do, when you need to bring the baby to the hospital or anything”</i> (Interview 1, child age 11 months).</p>
<p>Theme 3: Parents’ preferred formats to receive health information regarding their child Subtheme 1: Written Information</p>	<p><i>“I think like-if there would be a pamphlet that describes the...sickness...not in a very scientific, but simple way...that how it happens, and what are the causes and what parents can do about that, or what are the way that we can protect the children more about this type of virus. (Interview 14, child age 1 year).</i></p> <p><i>“I think pamphlets are good. Maybe if parents bring their kids in for flu shots, that can be kind of...given to them. Like a pamphlet about bronchiolitis ‘cause I didn’t know about about it until it happened to my kids.”</i> (Interview 1, child age 11 months)</p> <p><i>“Because bronchiolitis is so hard on newborns, um...part of the discharge package, when you’re leaving um, the hospital from having the babies might not be a bad idea.”</i> (Interview 8, child age 10 weeks).</p>
<p>Subtheme 2: Online sources</p>	<p><i>“Well, there’s the...Canadian Pediatric Society. There’s like Health Kids. I guess that knowing that these websites-that you can trust, exists. (Interview 3, child age 14 months)</i></p>

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	<p><i>“Other people don’t like reading, so watching videos, I think that works...but sometimes people need to see words written, or sometimes-like in Canada, we have language barriers. So I feel with information in the video-is too fast. (Interview 15, child age 6 weeks)</i></p> <p><i>“...social media or something, it’s something I would probably ignore-wouldn’t notice.” (Interview 10, child age 2 years).</i></p>
<p><i>Subtheme 3: Verbal Communication</i></p>	<p><i>“I think...the best way [to deliver information] is person to person. To be honest.” (Interview 15, child age 6 weeks)</i></p> <p><i>“For me, it’s been having a good pediatrician-like, someone I know that I can call.” (Interview 2, child age 3 months).</i></p> <p><i>“I do have a lot of nursing friends. And so, I text them and...they-like they’re moms as well. So they-they have pretty good input. (Interview 1, child age 11 months.)</i></p>

Appendix A

Interview Guide

Bronchiolitis

Parents will be interviewed to understand their experience having a child with bronchiolitis. Semi-structured interviews will be conducted with parents in order to get their “narrative” or experiences. The following questions will be used to guide these interviews. Being true to semi-structured interview techniques, interview questions will start broad and then move to the more specific.

1. Tell me about your experience having your child experience bronchiolitis.
 - a. What were the symptoms? How was your child behaving? How did you know they were sick? Has this happened before?
 - b. When did you decide to take them to the emergency department (ED)? Why did you decide to go to the ED?
 - c. Did your child’s illness affect your day to day activities? Were you getting the usual amount of sleep? How did it affect your family? (partner other kids)
2. Tell me about your child that was ill.
 - a. How old is your child? How was your child ill? How were they feeling? Describe this to me. Were they ‘out of sorts’? Were they eating and sleeping as they normally would? Did they miss their usual activities?
 - b. Has your child previously had bronchiolitis? If so, how many times? How was this time different? Was it different? What time of year?
3. Can you tell me about any thoughts or feelings you were experiencing during this time?
 - a. Were you worried, scared, nervous? Was it stressful? If so, how was it stressful?
4. Tell me how prepared you felt during the experience.
 - a. Did you feel confident in what to do to care for your child? Were you confident that you made the right choice to go to the ED? Did you go to your doctor or call the doctor before going to the ED? Did you call or talk to anyone else to seek advice, such as a friend? Family member? Other health care professional?
5. Did you have all of the information you needed to make decisions about when to seek healthcare? Tell me more about that.
 - a. Did you look for information when your child first became ill? Did you look for information about whether or not to go to the ED or see a doctor?
 - b. Where did you find information? What did you find? Did you find anything that was helpful? If so what was it and where did it come from?
 - c. Where would you typically look for health information for your child? Have you found information in the past? If so, what type of information was it and was it helpful? What do you think would makes information useful?

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3 6. Do you use social media?
 - 4
5 a. If so, did you look for information or ask questions on social media? Would you use social media
6 as a place to get or ask for health information for your child? Which social media platforms do you
7 use (Facebook, Instagram, snapchat, other).
8
- 9 7. What did you do to manage symptoms of bronchiolitis? (any techniques you used, for example, giving
10 Tylenol, talking with family/friends, etc.)
 - 11 a. How did you feel about your treatment regime? Did you feel confident in what you did? How did
12 your child respond to this?
13
- 14 8. How was your experience in the ED? Tell me about it.
 - 15 a. Did you have to wait very long? Approximately how long? How were you feeling during your
16 wait? How was your child feeling? Did you find things for your child to do while waiting? Tell me
17 about your interactions with the healthcare team. Was it an overall positive experience? If so, what
18 made the experience positive? If not, what made the experience negative?
19
- 20 9. Tell me about when or how your child was diagnosed with bronchiolitis – were any tests done? Any
21 medications ordered?
 - 22 a. What tests were done? Were these tests explained to you and why they were necessary? Were you
23 uncomfortable with any of the tests that were done (blood work, xrays, other)? If so, what made
24 you uncomfortable about them? How was your child during these tests - were they nervous,
25 anxious, crying, etc? Do you feel you got all the information you needed about what was
26 happening?
27
- 28 10. What strategies were put in place by health care professionals to help your child? (for example,
29 giving/prescribing medication). Did they ask you to do anything? If so, how comfortable were you with
30 that? Did they ask you what you have already tried?
 - 31 a. Did they give you any information before you went home from the ED? If yes, what did they give
32 you? Did they give you any advice for what to do at home? When to see your doctor? or when to
33 come back to the ED?
34
- 35 11. How did your child manage the experience? How did you feel about the outcome of this situation? Did it
36 go as expected for you?
 - 37 a. Was your child anxious, nervous? Did everything go as you had hoped or planned? Did you have
38 any follow up – other tests, going back to the doctor?
39
- 40 12. If presented with the same situation again (your child being ill with bronchiolitis), would you do anything
41 differently? If so, please tell me.
 - 42 a. How would you make a decision about whether or not to go to the ED? Would you look for
43 information before going this time? Where would you look or who would you ask for advice?
44
- 45 13. If the health system were to have information for parents, what do you think would be the best way to get it
46 to parents? Through their website, call line, advertisements, social media, public health clinics, doctors'
47 offices, etc.?
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