Research Article

A Community-Guided Approach to Bronchiolitis: A Needs Assessment and Illness Perception Study

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Abstract
The factors influencing caregivers' understanding of pediatric respiratory diseases, such as bronchiolitis, can guide patient care and the acceptability of treatment methods within the healthcare system. This study aims to identify illness perceptions and perform a needs assessment among caregivers of children diagnosed with respiratory diseases. This is a prospective, cross-sectional, questionnaire-driven study of a representative sample of caregivers whose children had an acute respiratory illness. The telephone-administered questionnaire was comprised of (1) demographic items; (2) illness perception questionnaire-revised (IPQ-R); and (3) items about personal barriers, the latter 2 of which employed a 5-point Likert response. Cronbach's alpha (α) was used to measure the internal consistency reliability for each item within the IPQ-R. The Pearson 2-tailed correlation coefficient was used to correlate questionnaire items. We included 75 caregivers whose children have been diagnosed with bronchiolitis (51%), reactive airway disease (RAD) (35%), asthma (33%), and wheezing (44%). We found no significance between the child's diagnosis and the site of recruitment. The most important components of the illness perception were illness coherence (α=0.849), psychological attributions (α=0.903), and barriers to diagnosis (α=0.633). Understanding caregivers' perceptions of respiratory diseases will lead to better treatment acceptance. We must clarify the terms used to define bronchiolitis from viral-induced wheezing, RAD, and the first asthma episode in older infants. Identifying caregivers' gaps in knowledge will help establish a cohesive approach to personalized treatment of respiratory diseases in children and their diagnosis.

Keywords
community engagement, respiratory care, survey data, medical decision making, emergency medicine, challenges

Introduction

Illness perceptions encompass patients' cognitive representations and emotional beliefs regarding their conditions,[1] influencing health behavior and treatment outcomes.[1–3] Illness representation relates to cognitive constructs associated with health threats, perceived vulnerability, optimism, self-efficacy beliefs, and perceptions of social norms.[4] Patient satisfaction and subsequent healthcare use are closely linked to the incorporation of patients' beliefs and emotional responses into medical care.[5] Effective health decision-making relies on health literacy and trust, with individuals with lower health literacy tending to trust alternative sources over specialist doctors.[6] Acceptability in healthcare interventions involves how both providers and recipients perceive appropriateness, influenced by cognitive

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and emotional responses.[7] Understanding caregivers' perspectives on pediatric respiratory diseases can inform treatment acceptability within the healthcare system.[8,9] Conducting a needs assessment before implementing or modifying treatment strategies helps identify unmet needs and challenges. However, there is limited literature on illness perceptions among caregivers of children with bronchiolitis regarding treatment acceptance. Therefore, this study aims to identify illness perceptions, perform a needs assessment, and explore attitudes and barriers among caregivers of children diagnosed with respiratory diseases like bronchiolitis.

Methods

Study Design

This prospective, cross-sectional questionnaire study sought to evaluate illness perceptions and needs among a representative sample of caregivers whose children experienced an acute respiratory illness. The questionnaire was conducted via telephone with parents/caregivers of patients who visited the emergency department (ED), pulmonary clinics, or satellite primary care clinics affiliated with our university-based pediatric hospital in Central Florida from January 1st and June 30th, 2021. Our not-for-profit healthcare system comprises over 70 satellite clinic locations throughout Florida, alongside the free-standing pediatric hospital with a 2.0 case mix index. The population we serve is over 50% of Hispanic or Latino origin, and over 50% have public healthcare insurance, which is representative of the community. The questionnaire was administered in English or in Spanish based on the participant's preference, to cater to our predominantly Spanish-speaking Hispanic

population, ensuring linguistic accessibility and cultural relevance. This study was approved by the Nemours Children's Health Institutional Review Board (1780328).

Data Collection Instrument

The questionnaire used for this study included the illness perception questionnaire-revised (IPQ-R).[10] The IPQ-R is a standardized and validated instrument that quantitatively assesses a patient's illness cognitive representation and causal attributions.[10,11] The questionnaire is comprised of 56 items on a 5-point Likert-type scale ranging from "disagree strongly" to "agree strongly." The principal components of the IPQ-R cognitive representation and causal attribution consist of 7 and 4 dimensions, respectively (Table 1). We created and added a personal barriers section to the questionnaire with the contribution of stakeholders, which included (1) the Family Advisory Council as patient advocates, (2) specialists in pediatric pulmonary medicine, (3) specialists in population health science, (4) specialists in infectious disease, (5) specialists in pediatric emergency medicine, (6) general pediatricians as representatives of the medical community, and (7) members of the medical system services. To identify qualitative concepts as part of the personal barriers section, we conducted qualitative, semistructured small-group discussions among our stakeholders. The interviewer re-worded or clarified questions to investigate topics introduced by the stakeholders. We performed the small-group discussion until we reached thematic saturation and proceeded to code the items into topics and themes, culminating in the identification of 5 dimensions. The content

Table 1. Principal Components of the Illness Perception Questionnaire-Revised (IPQ-R) and Barriers.

Domains	Scales	Meaning of the perception	No. of Items
Cognitive representation			
I	Timeline acute/chronic	Duration of the illness, as passing quickly or not	6
II	Timeline cyclical	Cyclical nature of the illness across time	4
III	Consequences	Impact of the illness	6
IV	Personal control	Caregiver's ability to control the illness	5
V	Treatment control	Effectiveness of any treatment or approach to control or cure the illness	5
VI	Illness coherence	The extent to which a caregiver understands the illness	5
VII	Emotional representations	Caregivers' emotional experience of their child's illness	6
Causal attribution			
I	Psychological attributions	Stress or worry, mental attitude, family problems, work, emotional state, personality	6
II	Risk factors	Heritable, diet, behavior, age, smoking, poor medical care in the past	6
III	Immunity	Germ, virus, pollution in the environment, immunity	3
IV	Accident or change	Chance, accident, or injury	2
Barriers			
I	Diagnosis	Barriers to diagnosis	5
II	Treatment	Barriers to treatment	5
III	Self-perceived understanding and access	Accessibility and understanding of disease	4
IV	Trust	Level of trust	6
V	Health literacy	Health literacy	7

validity index was computed for each item and revised as needed.[12] The final questionnaire consisted of 16 sections (plus demographics). Instrument revision included changes to the barrier section of the questionnaire, item wording, matrix, and format only if there was near universal consensus of their meaning. Iterative changes were made to the barrier section based on suggestions and comments obtained from the stakeholders and were revised and reduced accordingly.[13] The final questionnaire is available upon request.

Study Population

We included children 4 years of age and younger at the time of recruitment with a prior diagnosis of bronchiolitis, reactive airway disease (RAD), wheezing, recurrent wheezing, or asthma, whose parents or caregivers consented to participate. Diagnoses included were based on the International Classification of Diseases, 10th edition (ICD-10): acute bronchiolitis unspecified (J21.9), acute bronchiolitis (J21), acute viral bronchiolitis (J21.8), respiratory syncytial virus bronchiolitis (J21.0), acute bronchiolitis due to the respiratory syncytial virus (J21.0), acute bronchiolitis with bronchospasm (J21), bronchiolitis due to human metapneumovirus (J21.1), history of bronchiolitis (Z87.9), adenoviral bronchiolitis (B97.0), bronchiolitis caused by influenza virus (J11.1), wheezing not otherwise specified (R06.2), and unspecified asthma, uncomplicated (J45.909). We excluded children aged 5 years or older, and patients with a history of prematurity and/or comorbidities (ie, chronic lung disease, bronchopulmonary dysplasia, bronchiectasis, cystic fibrosis, congenital heart disease, immunodeficiency, neurologic condition).

Outcome Measures

Primary outcome measures included the identification of cognitive representation of illness, and causal attributions of caregivers whose children had a respiratory illness; the identification of personal barriers of caregivers whose children had a respiratory illness; and the correlation between the IPQ-R scales and personal barriers. Secondary outcomes include demographics.

Statistical Analysis

Data were analyzed using descriptive statistics for each item to describe the cognitive representation, causal attribution, and personal barriers. Categorical variables were analyzed using frequency and percentages. Continuous variables were analyzed using means and standard deviation if normally distributed, or median and interquartile ranges (IQR, [Q1-Q3]). The level of agreement was measured as a conceptually continuous variable ranging from 1 to 5 with 1 being "Strongly disagree" and 5 being "Strongly agree." The mean and total scores for each subscale were calculated. The internal consistency reliability for each subscale within the IPQ-R was assessed using Cronbach's alpha (α) statistic ranging from 0 to 1 where a higher value indicates a higher correlation among the items.

High Cronbach's alpha values indicate that response values for each participant across a set of questions are consistent.[14] An alpha score higher than 0.7 was characterized as acceptable. The correlation between questionnaire items and subscales was performed with a Pearson 2-tailed correlation coefficient. Assuming values of at least 10% for each variable, applying the rule of 10 for logistic regression,[15] we estimated a sample size between 75 and 150 usable surveys. A P-value less than .05 was considered statistically significant, with an alpha of 0.05, a beta of 0.8, and a confidence interval of 95%. The Statistical Package for the Social Sciences (SPSS) 28.0 was used for all analyses.

Results

We identified 700 patients who visited the ED, pulmonary clinics, or satellite primary care clinics with the diagnoses of interest during the study period. One-hundred seventy-two patients (25%) did not have a documented telephone number, 70 caregivers (10%) declined to participate in the study, and 427 (61%) did not answer the phone, requiring a callback. Out of 458 potential participants, we screened 150 caregivers (33%), and 75 were surveyed after meeting the inclusion criteria (100% completion rate). The time lag between the children's age from a prior diagnosis to the time of recruitment ranged from 3 months to 4 years. The median child age was 3 years (IQR, 2-4 years). Most caregivers were of Hispanic or Latino ethnicity (41, 55%), followed by White or Caucasian (22, 29%). The most common healthcare coverage was public (40, 53%), followed by private insurance (21, 28%). The non-

Table 2. Principal Components Analysis of the Illness Perception Questionnaire-Revised (IPQ-R) and Barriers.

Scales	Alpha (α)
Cognitive representation	
Timeline acute/chronic	0.829
Timeline cyclical	0.761
Consequences	0.818
Personal control	0.705
Treatment control	0.599
Illness coherence	0.849
Emotional representations	0.813
Causal attribution	
Psychological attributions	0.903
Risk factors	-
Immunity	-
Accident or change	-
Barriers	
Diagnosis	0.633
Treatment	-
Self-perceived understanding and access	0.540
Trust	-
Primary care provider	0.923
Emergency department	0.974
Pulmonary provider	0.957
Health literacy	-
Acceptance of tool	0.785

mutually exclusive distribution of respiratory diseases among children was bronchiolitis (38, 51%), RAD (26, 35%), wheezing (33, 44%), and asthma (25, 33%). Most recruited caregivers came from the ED (67, 89%). We found no statistical significance between respiratory disease and recruitment location. Most caregivers identified that they spoke and wrote English (71, 95%) and/or Spanish (46, 61%) fluently.

The Cronbach alpha for selected subscales is presented in Table 2. The cognitive representation subscale ranged from 0.59 for the treatment control to 0.84 for the illness coherence dimension. Among the cognitive representation subscale, illness coherence (α=0.849) which represents the perception that the caregiver understands the illness was found to be most often correlated with other study variables. Greater illness coherence of an acute pediatric respiratory illness was correlated with a greater sense of personal control ($r=0.31$, $P<.01$), less emotional reaction ($r=-0.34$, $P<.01$), less psychological burden ($r=-0.36$, $P<.01$), fewer barriers to diagnosis ($r=-0.22$, $P<.05$), lower misunderstanding of the treatment goal ($r=-0.52$, $P<.01$), and less mistrust of the primary care provider (PCP) ($r=-0.23$, $P<.05$). There was no correlation between illness coherence and receiving education on the patient's current illness from a provider. Among the causal attribution subscale, psychological attributions (α=0.903) such as stress, worry, emotional state, and mental attitude were found to be most often correlated with other study variables. Immunity, however, received the highest endorsement of agreement among caregivers (41, 54%). Among risk factors, 37% (28) of caregivers believed that a respiratory illness was hereditary and 35% (26) believed that it was due to age. Among the barrier subscale, barriers to receiving an accurate diagnosis (α=0.633) were found to be most often correlated with other study variables. Barriers to diagnosis are associated with a chronic illness ($r=0.48$, $P<.01$), cyclic illness ($r=0.34$, $P<.01$), negative consequences ($r=0.35$, $P<.01$), less illness coherence ($r=-0.22$, $P<.05$), more psychological burden ($r=0.36$, $P<.01$), and mistrust of the ED ($r=0.39$, $P<.01$). The agreement among caregivers about the presence of barriers yielded 26% (20) for diagnosis, 58% (44) for treatment, 15% (11) for self-perceived understanding and access, 4% (3) for trust, and 5% (4) for health literacy. Among the barrier subscale, trust shows the highest internal consistency, and reliability, and was most often correlated with health literacy. The correlation between barriers in trust and health literacy is presented in Table 3. Overall, receiving education on the patient's current illness from a provider leads to less mistrust in a specific clinical setting ($P<.05$). About 5% (4) of caregivers identified a language barrier.

Discussion

Illness perception involves a patient's cognitive appraisal and personal understanding of a medical condition and its potential consequences.[16,17] It focuses on how an individual, in this case, a caregiver experiences and mentally frames living with a

Table 3. Correlation Between Barriers in Health Literacy and Mistrust.

Scales	Mistrust		
Barriers—Health Literacy	PCP[a]	ED[b]	Pulmonary
Received education—PCP[a]	−0.499**	−0.297**	−0.091
Received education—ED[b]	−0.230*	−0.695**	−0.095
Received education— Pulmonary Clinic	−0.179	−0.387**	−0.902**
Acceptance of tool	−0.337**	−0.625**	−0.584**

[a]Primary care physician.
[b]Emergency department.
**Pearson correlation is significant at the 0.01 level (2-tailed).
*Pearson correlation is significant at the 0.05 level (2-tailed).

pediatric respiratory disease[3,17]; and whether their distress is associated with symptoms, causes, consequences experienced, and treatments. The cognitive representation component refers to the mental processes involved in acquiring, processing, and using knowledge. It also encompasses the concepts and attributes that reflect a person's comprehension and knowledge, in this case of a pediatric respiratory disease. Our findings show that within the cognitive representation, the extent to which caregivers understand the disease (ie, illness coherence) is most significantly correlated with the presence of barriers. However, these correlations show questionable magnitude, possibly due to the low sample size, the complexity of the respiratory disease, or the specificity of personal barriers to a particular population.

Our findings show that caregiver trust varies between provider specialties. Mistrust of the PCP is related to less illness coherence; hence, caregivers who do not trust their PCP have less understanding of the disease. The PCP is trusted more than providers in the ED, who are trusted more than the pulmonary subspecialist. A potential explanation is that PCPs can foster a more established relationship with patients and caregivers over extended periods due to continuity of care, in comparison to ED providers within the fast-paced nature of the ED, or subspecialists who provide visits spaced by prolonged periods. Another reason might be that conditions that are acute and/or cyclical might require more interaction with ED providers as emergencies are recurrent. This might also result in higher mistrust between caregivers and medical providers in the ED. Most studies have developed clinical guidelines for the diagnosis and management of bronchiolitis in the ED and acute care,[18,19] but there is seldom any information on what that may look like in primary care.[20] Hence, the best approach to mistrust is to address diagnostic and treatment incongruencies at the primary care level. Mistrust is correlated to lower acceptance of a diagnosis or therapeutic tool and a delay or variability in diagnoses. Receiving education about an illness correlates with decreased mistrust but is provider-specific. The trust developed in one provider does not transfer to trust in another provider. Literature states that there is strong evidence for positive influences

of patient-centered care and that caregivers prefer to seek health information directly from a provider that is considered easy to understand and credible, which may vary between providers.[21,22] Causal attribution of illness influences the type of treatment patients seek and the actions they take to control symptoms.[23] The beliefs about an illness's etiology may affect the patient's emotional response, particularly in illnesses in which the etiology is unclear. Caregivers' perceptions of the causes of respiratory disease (ie, causal attribution component) were not as significant as their perceptions of the disease itself (ie, disease chronicity, consequences, sense of control, emotional experience) or their perceptions of barriers to an accurate disease diagnosis and treatment. This shows that caregivers seem to care more about the psychological burden of respiratory illnesses than its etiological component. Constructs that have been identified as contributing to variations in the diagnosis and management of disease include uncertainty about clinical practice, the value of clinical guidelines, and tensions between individual and organizational practice.[24] Receiving education does not correlate with caregivers' perceived understanding of the disease or treatment (ie, illness coherence). Ultimately, the barrier to understanding the disease is the process of diagnosis. Scant literature has described parent expectations as drivers of utilization. Conversely, parents generally report a lack of expectations for tests/treatments and that tests/treatments did not improve their experience of care.[25] Hence, the problem becomes the diverse approach to the treatment based on patient diagnosis. To improve caregivers' buy-in, there needs to be a standardized approach such as a tool or the implementation of personalized medicine that can be applied to the diagnosis of the respiratory illness, which may drive the less-is-more approach to bronchiolitis care. This finding helps to justify our study design, where we included the conditions of asthma, RAD, recurrent wheezing, and bronchiolitis. Authors have failed to elucidate or clarify the differences between early childhood asthma, RAD, recurrent wheezing, and bronchiolitis.[26] For example, the term "reactive airway disease" has no agreed-upon definition and based on the Canadian Thoracic Society and Canadian Pediatric Societies' recommendations, the term should no longer be used.[27] Furthermore, a first episode of viral-triggered wheezing under the age of 2 years may be labeled bronchiolitis, whereas the recurrence of wheezing may be called preschool asthma.[26] Lastly, studies suggest that bronchiolitis early in life is a major risk factor for subsequent wheezing episodes and asthma.[28–30] Whether bronchiolitis chronologically precedes recurrent wheezing, RAD, or asthma in susceptible children is uncertain.[31] What remains clear is the need to develop definitions that may be used in the diagnosis of children with respiratory diseases. This information is necessary to develop effective diagnostic, therapeutic, and communicative approaches to facilitate joint medical decision-making among providers and caregivers, as well as to improve caregiver understanding of the disease and decrease associated barriers to medical care.

Limitations

Our study faces the limitations inherent to all questionnaire-based research, such as a moderate response rate. This questionnaire was disseminated among a specific subset of caregivers who had visited the ED, pulmonary clinics, or satellite primary care clinics belonging to our university-affiliated, free-standing pediatric hospital in Central Florida, which affects its generalizability. Given that the recruitment of caregivers includes a wide time lag ranging from 3 months to 4 years, our population may have been subjected to telescoping bias. Our results may overestimate the level of knowledge and awareness of pediatric respiratory illnesses when considering that the caregivers who chose to participate may have been more knowledgeable than those who declined to participate in the study. We did not inquire about the caregiver's education level, socioeconomic status, or social determinants of health which play a role in the caregiver's understanding of a disease. We did not complete a full principal components analysis to identify factors within the IPQ-R as there was not a sufficient sample size to do so meaningfully. Recall bias may be present in those participating in the telephone questionnaires and underrepresentation of certain demographic groups regarding illness perception and needs assessment in the community, such as gender of the caregiver or cultural background, may be present. This study benefited from the utilization of a standardized and validated questionnaire on key components of illness perception. The barriers component of this questionnaire was developed using a community-guided approach through continuous stakeholder engagement. The barriers put forth by the stakeholders may be particular for the population under study or the geographical location where the study took place,[32] and therefore may not be generalizable.

Conclusion

Understanding caregivers' perceptions of respiratory diseases will lead to better acceptance of treatment. We need to standardize the language used to talk to families. Our aim should be to clarify and minimize the clinical difficulties of differentiating acute bronchiolitis from viral-induced wheezing, RAD, and the first episode of asthma in older infants. Therefore, creating coherence throughout the healthcare system in the diagnosis and treatment of respiratory diseases should translate to better acceptance of treatment. Identifying caregivers' gaps in knowledge will help establish a cohesive approach to personalized treatment of respiratory diseases in children and their diagnosis.

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