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Bronchiolitis: when the conventional alone does not work, let's integrate!

Stollar, Fabiola

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**UNIVERSITÉ
DE GENÈVE**
FACULTÉ DE MÉDECINE

Clinical Medicine Section,
Department of Pediatrics, Gynecology and
Obstetrics

**“Bronchiolitis: when the conventional alone does not work,
let's integrate! ”**

Thesis submitted to the Faculty of Medicine of
the University of Geneva

for the degree of Privat-Docent
by

FABIOLA STOLLAR

Geneva

2024

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ABSTRACT

Introduction: Bronchiolitis is the leading cause of lower respiratory infections in infants, particularly those under one year old. Despite decades of extensive research on this condition, current management strategies primarily emphasize supportive care. While these measures are essential, they are inherently limited as they focus solely on the immediate needs of the child without addressing the broader implications of the disease. This creates a significant gap in managing the wider impacts and consequences of Bronchiolitis. **Aim:** this narrative review aims to provide a comprehensive exploration of the psychological, emotional, social, and economic impacts of Bronchiolitis hospitalization on infants, parents, and families, as well as the short- and long-term health consequences for the infant. The ultimate objective is to contribute to the development of family-centered care models that account for the holistic needs of patients and their families. Such an approach allows healthcare providers to go beyond physical treatment, supporting the emotional and psychological well-being of the entire family. The review also seeks to summarize current knowledge, identify emerging trends, and highlight gaps in the existing literature. **Methods:** A literature search was conducted using PubMed, Embase, and PsycINFO from their inception to the end of August 2024. Studies were selected based on predefined criteria, and data were analyzed using a narrative synthesis approach. **Results:** The findings indicate that Bronchiolitis significantly impairs the quality of life in infants, particularly in premature infants and those requiring ventilatory support, with persistent effects on feeding, sleep, and behavior lasting long after hospitalization. Parents often experience substantial emotional distress, including anxiety, guilt, depression, and symptoms of post-traumatic stress disorder, which can persist beyond their child's discharge. Family dynamics are also profoundly affected, with daily routines disrupted and financial strain emerging as a significant concern. **Conclusions:** Bronchiolitis hospitalization has profound and lasting effects on both infants, parents, and their families, reaching beyond immediate health issues to encompass significant psychological, emotional, and economic challenges. Addressing these impacts requires a comprehensive, family-centered approach that includes enhanced support services and strengthened communication strategies.

ABBREVIATIONS

CHD – Congenital Heart Disease;
HRQoL – Health-Related Quality of Life;
IBHQ – Impact of Bronchiolitis Hospitalization Questionnaire;
ICU – Intensive Care Unit;
ITQOL – Infant/Toddler Quality of Life Questionnaire;
MeSH – Medical Subject Headings;
MMAT – Mixed Methods Appraisal Tool;
PICU – Pediatric Intensive Care Unit;
PREMs – Patient-Reported Experience Measures;
PROMs – Patient-Reported Outcome Measures;
PTSD – Post-Traumatic Stress Disorder;
QALY – Quality-Adjusted Life-Year;
QoL – Quality of Life;
RCT – Randomized Controlled Trial;
RSV – Respiratory Syncytial Virus;
HUG – University Hospitals of Geneva.

"There is no such thing as a baby; there is a baby and someone."

D. W. Winnicott

1. INTRODUCTION

1.1 The burden of Bronchiolitis

Bronchiolitis is the most common cause of lower respiratory tract infections in infants, particularly during their first year of life, and represents a significant global health burden. The disease primarily affects children under one year old, with peak incidence occurring between three and six months. Bronchiolitis is responsible for approximately 3.4 million hospitalizations worldwide yearly, imposing an estimated annual healthcare cost of over \$700 million.(1,2)

Despite decades of extensive research, no pharmacological treatments have been universally recommended for the routine management of Bronchiolitis, largely due to inconsistent evidence of their efficacy.(3–5) Additionally, although multiple studies have demonstrated the lack of benefit from these treatments, and the American Academy of Pediatrics explicitly advises against their routine use, they continue to be administered in clinical practice.(6)

Recent advances, such as Nirsevimab, show great promise in reducing hospitalization rates associated with Respiratory Syncytial Virus (RSV). A single dose of Nirsevimab has been shown to protect healthy infants, both term and preterm, from RSV-related lower respiratory tract infections (LRTI) requiring medical care, hospital admissions, and severe RSV cases. This suggests that Nirsevimab could significantly transform the approach to infant RSV disease by reducing a major cause of morbidity and alleviating the burden on caregivers, clinicians, and healthcare systems.(7) Palivizumab, another monoclonal antibody, has been available for several years for RSV prevention. A recent Cochrane review found that it reduces RSV infections, the number of wheezing days, and hospitalizations. However, its high cost limits its use to a specific group of patients, and it requires monthly administration, further restricting accessibility.(8)

While advances like Nirsevimab and Palivizumab offer promising preventive options for RSV-related Bronchiolitis, they do not address all cases and aspects of the disease.(9)

Bronchiolitis can be caused by viruses other than RSV, and once the disease is established, these preventive treatments have little to offer in terms of management. As a result, effective treatment often depends on supportive care once hospitalization becomes necessary.

The current standard of care in Bronchiolitis is mainly supportive, focusing on maintaining adequate hydration and oxygenation to alleviate the symptoms and support the child through the illness.(10) These supportive measures, while crucial, are inherently limited as they

address only the immediate needs of the child and do not mitigate the disease's broader impact. The focus on physical symptoms overlooks the significant psychological and emotional toll that Bronchiolitis and its management impose on infants and their families. Infants are susceptible to their environment, especially in their early years, where their emotional and physical well-being is deeply intertwined with their caregivers' mental states.(11) Specifically, maternal distress has been shown to influence the infant's stress response, potentially exacerbating or even triggering health problems like Bronchiolitis.(12,13)

In a compelling article,(14) Adgent MA et al. emphasize the importance of understanding maternal exposure to psychosocial and traumatic stress, that may contribute to viral Bronchiolitis. The development of the immune system and lungs during pregnancy is regulated by interactions between the immune, neural, and endocrine systems, which can be disrupted by maternal stress.(15–18) Maternal stress during pregnancy has been associated with a shorter time to the first infection in infancy,(19) increased risk of Bronchiolitis and respiratory illness,(20–22) and respiratory conditions like wheezing and asthma in childhood.(23)

Recent studies suggest that maternal stress affects child respiratory health not only during pregnancy but also due to stressors before pregnancy, potentially resulting in long-term disruptions, such as altered cortisol production or inflammation.(24–26)

To complicate matters further, hospitalization for Bronchiolitis itself is a profoundly stressful experience for both the child and the parents. Disruptions to regular routines, such as breastfeeding, can further exacerbate this distress. For the infant, the hospital environment can be frightening, and the necessary medical interventions, such as oxygen therapy and nasal suctioning, can be uncomfortable or even painful.(27–29) In addition to feeding and oxygen saturation problems, infants with Bronchiolitis suffer from seemingly painful coughs, disrupted sleep, frequent awakening at night, and the need for constant monitoring further compound the infant's distress. Moreover, sleep disturbances during critical developmental periods have been linked to adverse neurodevelopmental outcomes, underscoring the importance of addressing these issues during hospitalization.(30)

For parents, the hospitalization of their child can trigger a range of emotional responses, including guilt, anxiety, and a sense of helplessness. Even though Bronchiolitis is generally considered a benign disease with a good prognosis, the experience of seeing their child suffer can be overwhelming. Many parents report feelings of isolation and a lack of involvement in their child's care, which can exacerbate these negative emotions.(31)

The connection between parental stress and child health is not a new concept. Since the 1950s, it has been the subject of extensive exploration, with key contributions from pioneering theorists like Françoise Dolto and Donald Winnicott. Both delved into the

significant impact of parental emotional well-being on child development. Dolto, for instance, emphasized that children's symptoms often reflect their parents' struggles, particularly within the mother-child relationship. Winnicott similarly argued that while children are born with growth potential, this potential can only be realized in a nurturing and supportive caregiving environment.(11,32)

1.2 Addressing unmet needs

The current literature on Bronchiolitis predominantly focuses on the efficacy of existing treatments, new therapeutic interventions, and clinical outcomes, such as improvements in respiratory distress, duration of hospitalization, length of oxygen therapy or nasogastric tube use, and the incidence of adverse reactions.(5,10,33) While these are undeniably important points, they represent only a narrow view of the disease's impact. There is a significant gap in the research regarding understanding the broader implications of Bronchiolitis on the emotional and psychological well-being of both the child and their family. This lack of attention to the relational aspects of Bronchiolitis care limits our ability to provide comprehensive support that addresses the full spectrum of needs of those affected by the disease.

Parents' need for support during Bronchiolitis hospitalizations represents a significant unmet need in healthcare. In urban centers like Geneva, where 40% of the population is made up of foreigners, the challenges of parenthood can be even more pronounced. Many families lack the extended support networks often relied upon in times of need, such as when a child is sick. This lack of support can exacerbate parents' stress and pressure, particularly those struggling to balance work, childcare, and other responsibilities.(34) When a child is hospitalized with Bronchiolitis, these challenges can become overwhelming, leading to a situation where parents are not only dealing with the stress of their child's illness but also with the fear that they are not able to provide the care their child needs. Parents often come to pediatricians seeking help not just for their child's physical symptoms but also for the emotional and psychological strain they are experiencing. In our experience, many express fears of inadvertently harming their child due to their feelings of being unable to manage the demands of caregiving, especially when they are exhausted and overwhelmed.

Moreover, healthcare providers face significant challenges during peak Bronchiolitis seasons, when hospitals are often overwhelmed with cases. The increased workload and the emotional strain of caring for critically ill infants can lead to stress and burnout among healthcare staff, affecting patient care quality. The emotional well-being of healthcare providers is closely linked to patient outcomes, with studies showing that stressed or

overworked staff are more likely to make errors, which can compromise patient safety and hinder the healing process.(35–37)

Given these multifaceted challenges, it is evident that the current approach to Bronchiolitis care is insufficient. There is a pressing need for a more holistic approach that considers the disease's emotional, psychological, and social dimensions is needed to provide comprehensive care for infants and their families. This approach should involve directly managing the child's health and physical symptoms while providing support and resources for parents/families and healthcare providers.

1.3 Challenging Misconceptions

The arrival of a child in a family is a momentous event, often bringing joy but also significant stress and uncertainty. Modern parenthood is fraught with pressures and expectations, many of which are influenced by societal myths and misconceptions. One of the most pervasive myths is that parents, particularly mothers, are innately equipped with the knowledge and skills to raise their children. This notion, often reinforced by societal expectations and cultural narratives, suggests that parenting abilities should come naturally and effortlessly from when a child is born.(38,39)

This unrealistic expectation can lead to feelings of guilt, anxiety, and inadequacy when parents inevitably encounter challenges in raising their children. The pressure to be a "perfect" parent, combined with the amount of information available on parenting, can create a sense of being overwhelmed and unsure, particularly during times of crisis, such as when a child is hospitalized.(32,38,40,41)

These feelings are often exacerbated by the misconception that healthcare providers have all the answers and are fully equipped to guide families through every aspect of their child's care. While pediatricians are trained to manage children's physical health, the psychosocial aspects of care often receive less attention in medical education and practice. Pediatricians are primarily taught to prevent illnesses, manage diseases, and monitor developmental milestones. However, due to time constraints and the focus on physical health, the broader psychosocial needs of the child and family are not always addressed as thoroughly as they should be.(42,43) This gap in care is particularly concerning given the growing body of evidence that underscores the importance of the family environment and parent-child relationships in determining a child's overall health and development, as previously discussed. In the same way that parents feel disempowered, healthcare providers may feel frustrated by the limitations of their role, as they are often unable to offer the comprehensive support that families need.(11,13,44–47)

1.4 Aims

This narrative review aims to comprehensively explore the psychological, emotional, social, and economic impacts of Bronchiolitis hospitalization on infants, parents, and families, as well as the short- and long-term effects on infant health. The goal is to contribute to the development of family-centered care models that address the full spectrum of needs of Bronchiolitis patients and their families. By adopting this approach, healthcare providers can not only treat the physical symptoms of the disease but also support the emotional and psychological well-being of the entire family. The review seeks to summarize current knowledge, identify research trends, and highlight gaps in the existing literature.

2. MATERIAL AND METHODS

2.1 Framework and Guiding Principles

This narrative review adheres to best practice guidance for reporting such studies.(48) It was conducted following the framework by Arksey and O'Malley,(49) which involves five key steps: identifying the research question, determining relevant literature, selecting studies, extracting data through mapping and charting, and synthesizing the results.

2.2 Research Question Formulation

The research question was formulated based on the PEO framework:

- **Population (P):**
 - **Primary Population:** Infants under one year old hospitalized for acute Bronchiolitis.
 - **Secondary Population:** Parents and families of these infants.
- **Exposure (E):**
 - **For Infants:** Hospitalization due to acute Bronchiolitis.
 - **For Parents/Families:** The lived experience of having an infant hospitalized for acute Bronchiolitis.
- **Outcome (O):**
 - **For Infants:** Psychological and emotional outcomes such as behavioral changes, stress levels, attachment issues, and general emotional well-being, as well as health outcomes like weight loss, wheezing, and feeding difficulties, both short—and long-term.

- **For Parents/Families:** Psychological and emotional impact, including stress, anxiety, and depression, alongside potential social and economic consequences resulting from the hospitalization.

Research question: Given the PEO framework, the specific research question guiding this narrative review is: "What are the overall impacts on infants under one year old hospitalized for acute Bronchiolitis, and how do these affect the psychological, emotional, social, and economic well-being of their parents and families during and after hospitalization?"

2.3 Search Strategy

To conduct this narrative review, a comprehensive literature search was performed across three major electronic databases, PubMed, Embase, and PsycINFO, from their inception to the end of August 2024. The aim was to identify studies that evaluated the impact of Bronchiolitis hospitalization on infants and their families, including parents, caregivers, and siblings. The search used a combination of Medical Subject Headings (MeSH), Emtree terms, and free-text keywords.

2.3.1 Search Terms

The following terms were used to structure the search:

- **Core Medical Terms:** "Bronchiolitis," "Acute Bronchiolitis," "Respiratory Syncytial Virus Bronchiolitis," and "Hospitalization."
- **Impact on Infants:** "Infant," "Neonate," "Newborn," "Psychological Impact," "Emotional Impact," "Health Outcomes," "Quality of Life," and "Developmental Outcomes."
- **Impact on Parents and Families:** "Parent," "Mother," "Father," "Caregiver," "Family," "Family Impact," "Siblings," "Stress," "Anxiety," "Depression," "Psychological Impact," "Emotional Impact," "Mental Health," "Burden," "Social Impact," "Family Functioning," "Economic Burden," and "Financial Burden."

Boolean operators (AND, OR) combined these terms to capture relevant studies. For instance, searches were conducted using terms such as ("Bronchiolitis" AND "hospitalization" AND "infant") AND ("parent" OR "family" OR "caregiver").

2.3.2 Database-Specific Strategies

- **PubMed:** A combination of MeSH terms and free-text keywords were used. An example of a search string applied was ("Bronchiolitis"[Mesh] AND "Hospitalization"[Mesh]) AND ("Parents"[Mesh] OR "Family"[Mesh] OR "Caregivers"[Mesh]).

- **Embase:** Searches were performed using Emtree terms, complemented by free-text searches. A representative search query was ('Bronchiolitis'/exp AND 'hospitalization'/exp AND ('infant'/exp OR 'newborn'/exp) AND ('family'/exp OR 'parent'/exp OR 'caregiver'/exp)).
- **PsycINFO:** Focused on the psychological and social impacts, using a query such as (Bronchiolitis AND hospitalization AND (infants OR newborns) AND (stress OR anxiety OR family impact OR psychological impact)).

2.3.3 Eligibility Criteria - Inclusion and Exclusion Criteria

Inclusion criteria:

- Focused on Bronchiolitis and associated hospitalization.
- Examined the impact on infants, parents, or families.
- Published in peer-reviewed journals.
- No language restrictions were applied.

Exclusion Criteria:

- Studies that did not meet the inclusion criteria.
- Articles that did not report original data (e.g., reviews, editorials, letters to the editor, case reports, congress abstracts).
- Studies where the population or exposure was not specified or described.
- Studies focused on conditions other than Bronchiolitis, non-hospitalized cases, and those not involving human subjects.

2.4 Study Selection

Titles and abstracts were screened to eliminate irrelevant studies. The full texts of the remaining articles were then reviewed in detail to ensure they met the inclusion and exclusion criteria. The initial search identified eleven articles, of which 9 were retained after removing duplicates. An additional ten articles were included based on references from these 9 articles. Ultimately, 19 studies were selected for inclusion in this review. A summary of the included studies can be found in Annex 1.

2.5 Data Extraction and Synthesis

Data extraction focused on study design, population characteristics, outcomes related to infant and family impacts, and key findings. To ensure accuracy and minimize bias, thorough cross-checking of the extracted data was conducted, and any uncertainties were addressed by re-examining the original studies.

2.5.1 Data Extraction (Mapping Out, Charting)

The extraction process was guided by a structured approach focusing on key domains of interest, ensuring consistency and reliability. The following categories were meticulously charted:

- **General Study Information:**
 - Author(s) and Year of Publication: To provide an overview of the research timeline and identify trends over time.
 - Study Design: Including the type of study to understand the methodological approaches used.
 - Country/Setting: The study's geographical location, context, and cultural and healthcare system differences may influence outcomes.
 - Funding Sources and Conflicts of Interest: To assess potential biases in the research.
- **Population Details:**
 - Sample Size: The number of infants and families included in the study to gauge the scale and generalizability of the findings.
 - Infant Demographics: Age, sex, and other relevant characteristics of the infants, such as pre-existing conditions or risk factors.
 - Family Demographics: Information about the parents or caregivers, including age, socioeconomic status, education level, and family structure, could influence the psychological and social outcomes.
- **Exposure Details:**
 - Hospitalization Characteristics: the severity of Bronchiolitis, the required care level (e.g., intensive care unit (ICU) admission), and any interventions received during hospitalization.
- **Outcomes of Interest:**
 - Psychological/Emotional Impact/Stress-Related Consequences: This includes measurements or descriptions of anxiety, depression, stress levels, and emotional well-being for both infants and their family members.
 - Short- and long-term health outcomes for infants: This encompasses outcomes such as wheezing, feeding difficulties, and persistent cough.
 - Social Outcomes: This includes information on changes in family dynamics, levels of social support, economic impacts (e.g., income loss, financial strain), and any reported long-term effects on the family unit.

2.5.2 Synthesis of Results

Because of the high degree of heterogeneity between studies, a narrative summary was employed to synthesize the findings from the included studies in this review. This narrative synthesis includes investigating the findings' similarities and differences and exploring patterns in the data. This approach was chosen to provide a clear and straightforward summary of the impacts of Bronchiolitis hospitalizations on infants and their families, focusing on psychological, emotional, stress-related, and social/economic outcomes.

2.5.3 Narrative Synthesis Process

- **Summarization of Findings and Reporting of Key Outcomes:**

The findings were synthesized through a structured narrative synthesis process, which involved summarizing key results from each study based on three primary domains. The results were organized into sections corresponding to the key outcomes of interest, including:

- Impact on infants.
- Psychological/Emotional impact on parents and caregivers.
- Social Outcomes, family dynamics, and economic impact.

- **Contextual Descriptions:**

- Study Context: The synthesis considered the context in which each study was conducted, such as the healthcare setting, cultural background, and socioeconomic factors. These contextual details were used to explain how different environments influenced outcomes.
- Impact of Hospitalization: The narrative described how the severity of the infant's condition and the availability of support systems affected the psychological and social outcomes for families.

- **Comparison Across Studies:**

- While maintaining a descriptive focus, the synthesis included simple comparisons across studies, noting where findings were consistent or where there were differences.
- Trends were discussed descriptively without formal statistical analysis.

- **Use of Direct Quotes (if qualitative data were included):**

- If qualitative studies were included, direct quotes from participants in the studies were used to illustrate key points and provide a more vivid description of the experiences reported.

This approach allowed for a straightforward presentation of the findings, making the results accessible and easy to understand while capturing the complexity of the families' experiences.

3. RESULTS

3.1 Impact on Infants

Numerous studies have demonstrated that infants with severe Bronchiolitis, particularly those requiring ventilatory support, experience significant and lasting reductions in physical functioning, overall health, and comfort, with effects persisting well beyond hospitalization. Rolfsjord et al. (2016) found a strong correlation between the severity of acute Bronchiolitis and long-term declines in infants' quality of life (QoL).(50) Similarly, Campbell et al. (2020) observed that infants who underwent intensive treatment experienced heightened discomfort and distress, with those needing ventilatory support showing the most pronounced impairments in terms of bodily pain and discomfort. These findings further emphasize the link between the intensity of medical intervention and the extent of QoL decline.(51)

Further research underscores the disruptive impact of hospitalization on infants' daily routines. Robbins et al. (2006) reported that about two-thirds of infants had difficulties with feeding, sleeping, and behavior at discharge, with symptoms such as coughing and wheezing persisting for several days.(52) In addition, Lapillonne et al. (2013) found that Bronchiolitis led to disturbed breastfeeding, feeding issues, and behavioral changes, such as increased crying and weight loss.(53) Preterm infants, in particular, face even greater challenges. Leader (2003) observed that preterm infants had significantly longer hospital stays, averaging 6.9 days compared to 3.4 days for full-term infants, and required more follow-up visits and extended recovery periods.(54)

RSV-related hospitalizations have a notable long-term impact on infants' health. Rolfsjord et al. (2015) documented that child with a history of Bronchiolitis, especially those with risk factors such as atopic eczema or a predisposition to asthma, had reduced quality of life (QoL) for up to nine months post-hospitalization. These children experienced more significant declines in general health and well-being, making them more vulnerable to persistent respiratory issues.(55) Likewise, Tessel van Dijk (2023) found considerable impairments in health-related quality of life (HRQoL), particularly concerning lung and gastrointestinal issues, even six months after discharge from the pediatric ICU.(56) Studies by Spuijbroek et al. (2011) and Díez et al. (2021) also reported lower HRQoL scores in children with RSV Bronchiolitis, particularly in areas related to physical functioning and overall health perceptions.(27,57)

Additionally, Leidy et al. (2005) reported that infants and children hospitalized for RSV exhibited poorer functional status, higher stress levels, and diminished overall health both during and after hospitalization, with symptoms such as wheezing and coughing persisting for up to 60 days post-discharge.(58) These findings underscore the importance of long-term

follow-up and intervention for infants recovering from Bronchiolitis, particularly those at higher risk for continued respiratory issues.

3.2 Psychological/Emotional Impact on Parents and Caregivers

The hospitalization of infants with Bronchiolitis places significant psychological and emotional stress on parents and caregivers. Studies consistently report elevated levels of anxiety, depression, and emotional strain, with many parents experiencing these challenges long after their child's discharge.

Rolfsjord et al. (2016) found that parents of infants with Bronchiolitis experienced significant emotional strain and challenges in time management during hospitalization and in the months following discharge. This strain was exacerbated by the severity of their child's condition, especially in cases involving prolonged hospital stays and intensive care treatments.(50) Furthermore, van Benthum et al. (2022) revealed that up to seven months post-ICU discharge, parents reported prevalence rates of post-traumatic stress disorder (6.1%), anxiety (18.8%), depression (6.1%), and distress (14.6%), underscoring the enduring psychological impact of Bronchiolitis on caregivers.(59)

Parents from remote areas encounter additional compounded stress when their child is hospitalized for Bronchiolitis. Kopacz et al. (2013) emphasized that these parents often felt overwhelmed by the sudden onset of their child's illness, experiencing guilt for not recognizing the severity sooner. Phrases such as "RSV is scary" and "Lots of stress; little rest" were commonly used to convey their distress, which was further intensified by logistical challenges and the long distances to medical facilities.(60)

It is also important to note that interactions with healthcare professionals significantly influence parental stress levels. Carbonell-Estrany et al. (2018) found that parents experienced significant distress, often linked to concerns about their child's condition and interactions with medical staff. Ongoing concerns about the possibility of readmission, along with the need for up-to-date medical information, were critical factors contributing to parental anxiety during and after hospitalization.(61)

Wrotek et al. (2023) identified that 37% of caregivers experienced heightened anxiety and depression during their child's hospitalization, with 17% reporting physical symptoms such as pain and discomfort.(29,62) Lapillonne et al. (2012) similarly found that parents faced substantial psychological distress, including feelings of guilt, uncertainty, and emotional responses such as anger and demoralization, often persisting for months post-discharge.(28) The main factors influencing the impact were the length of the hospital stay and parents' educational level.

The emotional distress of parents, particularly mothers, was further highlighted by Peeler et al. (2015),(63) who found that the inability to comfort or care for their child during

hospitalization physically compounded fears of their child's potential death. Additionally, Leidy et al. (2005) reported that the most stressful experiences for parents involved witnessing their child undergo medical procedures and adjusting to changes in parental roles, which impacted family cohesion and adaptability. These issues often persisted for up to 60 days after discharge, indicating a need for long-term psychological support for families.(58)

For instance, Campbell et al. (2020) captured the emotional toll of the situation:(51)

- *"We had to quit everything we were doing because I was with him in the hospital for four days. My husband and my daughter were affected as well. Like he had to drop everything he was doing to come help us."*
- *"People were kind of like staring—outside of our room. There was a crowd of doctors and nurses, but nobody was communicating with us about what was happening. So that was hairy because we could tell they were concerned or watching him, but they wouldn't communicate with us."*

Similarly, parents in Kopacz et al. (2013) expressed their intense emotional responses:(60)

- *"When I heard my baby wasn't getting enough oxygen and had to be admitted, I panicked."*
- *"All of a sudden, we are getting this new vocabulary, and with the stressful time, it doesn't stick as much."*

Pokrzywinski et al. (2019) further illustrates the broad emotional and logistical challenges faced by parents:(64)

- *"I missed my fifth anniversary with my husband. I canceled two meetings, one work-related and one personal."*
- *"It was very difficult as I have 3 other children staying at their grandparents' house. It was hard since they didn't see me at all during the hospitalization. It took a huge toll on all of us. It was very draining."*
- *"It was like waking up after a bad dream."*
- *"This has been very stressful. I wish there had been some way I could have prevented my child from getting sick."*

3.3 Social Outcomes, Family Dynamics, and Economic Impact

The hospitalization of infants with Bronchiolitis places a significant social, emotional, and financial burden on families, affecting both their immediate and long-term well-being.

Rolfsjord et al. (2016) found that families of infants who experienced prolonged hospitalization or intensive treatments struggled to balance caring for their hospitalized child with work commitments and attending to the needs of other children, leading to disrupted

routines that often persisted long after the child's discharge.(50) Robbins et al. (2006) highlighted that disruptions in feeding and sleeping routines further complicated the family's ability to return to normalcy, requiring parents to take additional time off work.(52) Campbell et al. (2020) also found that daily routines were disrupted, leading to increased tension between parents and feelings of guilt related to their other children. The study also highlighted family disruption due to missed work, which resulted in a financial burden and shifting family roles.(51) Similarly, Custovic et al. (2024) reported that 57% of parents experienced moderate to severe emotional impacts and mental fatigue affecting daily life and professional responsibilities. Missed workdays, healthcare costs, and childcare absences added to the financial burdens, increasing overall stress levels.(65)

The challenges faced by parents did not end with discharge; Lapillonne et al. (2013) noted that organizational difficulties and financial strain persisted for up to three months post-discharge. Parents reported physical symptoms such as fatigue and sleep disturbances, alongside decreased income and increased expenses. This also affected their behavior toward the hospitalized infant, with parents becoming more protective. Additionally, siblings experienced sadness and worry, as the entire family dynamic was affected by the hospitalization.(53)

The financial burden associated with the hospitalization of infants with Bronchiolitis is significant, as illustrated by Leader et al. (2003), who found that families of preterm infants faced exceptionally high out-of-pocket costs, averaging \$643.69 compared to \$214.42 for full-term infants. The total economic impact, including lost productivity, reached \$4,517.07 per preterm infant and \$2,135.30 per full-term infant. These costs extended beyond immediate medical expenses, encompassing the broader financial impact of missed work, travel expenses, and ongoing care needs.(54) Wrotek et al. (2023) found that the financial stress often persisted well after the child's discharge, with routine disruptions, lost productivity, and economic burdens continuing to affect caregivers' well-being and the broader family dynamic.(29) In line with this, Carbonell-Estrany et al. (2018) highlighted that many parents were forced to rearrange their work schedules or take unpaid leave, further exacerbating financial stress.(61)

Díez et al. (2021) further underscored the substantial healthcare costs associated with managing RSV, revealing that most episodes required pediatrician visits (95.4%), followed by emergency department visits (60.5%), and hospitalizations (34.9%), with 2.3% requiring ICU care. The median cost per RSV episode was approximately €713.45, resulting in a total cost of €193,410.07 for all cases examined.(27)

Pokrzywinski et al. (2019) also emphasized the ongoing economic strain experienced by families, identifying nine key themes affecting caregivers, including routine disruptions, separation from other children, negative impacts on family relationships, financial stress, and

productivity loss. Many caregivers, particularly mothers, reported significant stress at discharge, with financial burdens persisting long after their child had returned home.(64) Families in remote areas faced even more significant challenges, as noted by Kopacz et al. (2013), who highlighted that parents in rural regions often had to navigate logistical difficulties related to medical transport and a lack of extended family support. These factors intensified both emotional and financial burdens, leading to additional travel and accommodation expenses that significantly impacted the overall effects of hospitalization.(60)

Finally, Peeler et al. (2015) highlights the significant social strain on families during hospitalization, illustrating the emotional toll through a caregiver's experience: *"It was very difficult as I have 3 other children staying at their grandparents' house. It was hard since they didn't see me at all during the hospitalization. It took a huge toll on all of us. It was very draining."* This statement encapsulates the challenges faced by families, emphasizing how hospitalization not only affects the hospitalized child but also disrupts family dynamics and contributes to the overall emotional burden on caregivers.(66)

4. DISCUSSION

As highlighted by the various studies presented in the results section, this review underscores the extensive and multifaceted impact of Bronchiolitis hospitalization on infants and their families. The psychological and emotional toll on parents and caregivers is profound, often lasting well beyond the hospital stay. Infants, particularly those born preterm, experience a significant decline in quality of life during and after hospitalization, further exacerbating family distress. The substantial social and economic burdens that families endure while trying to balance caregiving with their professional and personal responsibilities frequently result in prolonged disruptions to daily routines and overall well-being.

Our review's findings align with existing literature; however, to the best of our knowledge, it is the first to provide a comprehensive overview of all impacts associated with Bronchiolitis hospitalizations in a broad and integrated manner. While the current literature on this topic comprises only four key reviews, as summarized below.

In the systematic review by Gates et al. (2018) only 14 studies met more than 50% of the criteria outlined by the Mixed Methods Appraisal Tool (MMAT). Among these, just 31% focused on hospitalization experiences, while the remaining studies addressed treatments, prophylaxis, and various other themes. Their findings revealed that many parents struggle with recognizing and managing Bronchiolitis symptoms, leading to significant stress and anxiety during hospitalization. The review stressed the importance of timely and effective

communication from healthcare providers to alleviate these concerns and enhance parental involvement in care.(31)

Glaser et al. (2022) conducted a systematic review assessing utility losses associated with RSV episodes. They identified only seven citations meeting their inclusion criteria, comprising two cohort studies, four modeling studies, and one synthesis. Their findings revealed substantial quality-adjusted life-year (QALY) losses for both children and caregivers, with losses associated with RSV exceeding those attributable to prematurity alone. This review underscored a significant gap in quality-of-life data for children with RSV, particularly for those who are not preterm, highlighting the necessity for more inclusive and comprehensive studies in this area.(67)

Díez-Domingo et al. (2014) provided a comprehensive overview of RSV's health, resource, and cost impacts. Their review highlighted the extended health effects of RSV, including long-term complications such as recurrent wheezing and asthma. Additionally, it noted increased healthcare resource utilization and direct and indirect costs associated with RSV, advocating for targeted interventions and effective prophylactic measures to address these impacts.(68)

Young M et al. (2021) explored the socioeconomic impact and healthcare resource utilization of RSV-related hospitalizations. They emphasized RSV's significant strain on healthcare systems and the considerable burden on caregivers. Their review detailed the high incidence of RSV-related lower respiratory tract infections in young children and its long-term consequences, such as recurrent wheezing and impaired lung function. They underscored the need for strategies addressing both immediate and long-term impacts of RSV.(69)

4.1 Strategies to Mitigate the Problem

To effectively address the challenges associated with Bronchiolitis hospitalization, several key strategies can be implemented:

- **Enhancing Support Services/ Community Resources:** Psychological counseling during and after hospitalization can alleviate parents' emotional stress. Developing tailored support programs can address individual family needs. Enhancing local support networks and services can provide practical assistance, especially to families in remote areas, reducing isolation and addressing logistical challenges.
- **Sensitizing and Training Healthcare Providers:** Training healthcare providers to recognize and empathize with the burdens faced by families can improve support and responsiveness, fostering a more supportive hospital environment.
- **Prioritizing Family-Centered Care:** Involving families more closely in care decisions and ensuring open, supportive communication with healthcare professionals can improve the hospitalization experience and reduce stress.

- **Creating Healing Environments:** Designing comforting spaces within hospitals and places such as the “meeting places” in Geneva,(70) can facilitate family interaction and offer a supportive atmosphere for parents and children.(71–73)
- **Advocating for Flexible Work Policies:** Employers and policymakers should promote flexible work arrangements and paid sick leave to ease financial burdens and allow parents to balance work and caregiving responsibilities more effectively.
- **Implementing Post-Discharge Follow-Up Programs:** Structured follow-up visits with healthcare providers can monitor recovery, address ongoing issues, and support families as they transition back to their daily routines.
- **Research and Policy Development:** Continued research and policy advocacy should aim to understand the long-term impacts of Bronchiolitis better and develop policies that address these challenges, ultimately improving outcomes for affected families.
- **Incorporating Complementary and Integrative Medicine:** Utilizing complementary and integrative medicine approaches can effectively reduce anxiety for infants and parents. These methods provide calming effects and foster a soothing atmosphere during hospitalization. Educating healthcare providers about the benefits of such interventions can further encourage their use, ultimately enhancing the overall care experience for families.(42,43,74,75)

4.2 Limitations of the current review:

Our review has several limitations. First, it was not conducted as a systematic review, nor did it employ a formal systematic analysis of the included studies. Nevertheless, given the significant heterogeneity across the studies, a narrative review was deemed the most appropriate approach to synthesize the findings, as previously mentioned. Second, the search process, assessment of methodological quality, data extraction, and synthesis were carried out by a single independent researcher. Although measures were taken to minimize potential biases, such as oversight from an experienced supervisor, the exact influence of these limitations on the results remains challenging to quantify. This may introduce a degree of personal bias. Finally, the studies included in this review exhibit several limitations themselves, which may further affect the interpretation of their findings. However, a key strength of this review is our in-depth description and analysis of these limitations, which is outlined below.

4.3 Evaluation of the Limitations in Studies Included in This Review

- **Sample Size and Generalizability:** Many studies, including those by van Benthum et al. (2022), Kopacz et al. (2013),(60) Spuijbroek et al. (2011)(57), Wrotek et al. (2023),(29,62) Leidy et al. (2005)(58), van Dijk et al. (2023)(56) and Peeler et al. (2015),(59,63) were limited by small sample sizes, which impact the generalizability of their findings. Additionally, studies such as those by Rolfsjord et al. (2015, 2016) and Pokrzywinski et al. (2019),(50,55) exhibited skewed response rates, further constraining the applicability of the results. Some studies, like Campbell et al. (2020) and Rolfsjord et al. (2015, 2016) also lack diversity in their samples, as they primarily included participants with higher education levels;(50,51,55) This may limit the representation of broader socioeconomic backgrounds. Generalizability is further limited in studies such as Lapillonne et al. (2013),(53) which primarily focused on a French-speaking population of mothers, thereby providing minimal insight into fathers' experiences. In addition, Díez et al. (2021) concentrated exclusively on the Spanish population,(27) while Kopacz et al. (2013) specifically examined Alaskan parents, further narrowing the applicability of their findings.(60)
- **Recall and Self-Reporting Bias:** Several studies, including those by Robbins et al. (2006) and Wrotek et al. (2023), relied on parental self-reports and recall, introducing potential bias.(29,52,62) The short recall periods may not capture full recovery. This issue is also noted in Campbell's et al. (2020) and Custovic et al. (2024) studies.(51,65) There was also potential recall bias in Leader et al. (2003), and Pokrzywinski et al. (2019).(54,64) In the study of Díez et al. (2021) about 50% of the questionnaires were completed at least 48 hours after the scheduled date, introducing the possibility of recall bias.(27) Several studies, including those by Robbins et al. (2006) and Wrotek et al. (2023), relied on parental self-reports and recall, which may introduce bias.(29,52,62) The short recall periods in these studies might not fully capture the extent of recovery. This limitation is also observed in the studies conducted by Campbell et al. (2020) and Custovic et al. (2024).(51,65) Additionally, potential recall bias was noted in the research by Leader et al. (2003) and Pokrzywinski et al. (2019).(54,64) In Díez et al.'s study, approximately 50% of the questionnaires were completed at least 48 hours after the scheduled date, further increasing the likelihood of recall bias.(27) Finally, the retrospective design of some studies, such as those by Carbonell-Estrany et al. (2018) and Pokrzywinski et al. (2019), introduces recall bias.(61,64) Additionally, self-selection bias in surveys, as highlighted in Custovic et al.'s study (2024), may result in a sample that does not adequately represent the target population.(65)

- **Validation and Measurement Issues:** Numerous studies, including those by Robbins et al. (2006), Lapillonne et al. (2012, 2013), and Díez et al. (2021), utilized new or adapted measures that lacked sufficient validation, which may compromise the reliability of their findings.(27,28,52,53)
- **Limited Demographic Data:** Many studies, including those by van Benthum et al. (2022), Spuijbroek et al. (2011), Kopacz et al. (2013) and Peeler et al. (2015) lacked detailed demographic data affecting the understanding of how factors such as educational level or socioeconomic status influence the impact of Bronchiolitis.(57,59,60,63)
- **Single-Center and Cultural Limitations:** Some studies, including those by Wrotek et al. (2023), were conducted at single centers or within specific cultural contexts, potentially limiting the generalizability of their findings to other settings.(29,62)
- **Duration and Timing of Assessments:** Variability in the timing of assessments across studies, such as those by van Dijk et al. (2023) and Leader et al. (2003), affects the comprehensiveness of the data regarding long-term effects.(54,56)
- **Data Collection and Analysis:** Several issues constrain the reliability of the findings, including limited evidence on construct validity (Lapillonne et al., 2013),(53) potential confounding factors (Leidy et al., 2005),(58) and the absence of independent cost verification and comprehensive assessment of post-discharge expenses (Leader et al., 2003).(54) Additionally, the study by Rolfsjord et al. (2015) employed controversial statistical adjustments for multiple testing, further complicating the interpretation of the results.(55)

4.3 Future research:

Future research should explore several critical areas to deepen our understanding and enhance support for families affected by Bronchiolitis. Investigating the long-term psychological and economic effects on families is essential, focusing on how ongoing psychological counseling and financial aid influence family stress and overall well-being. Additionally, examining family-centered care approaches can reveal how involving families in care decisions and improving communication with healthcare professionals impacts their experience and stress levels.

Future research should investigate several critical areas to enhance our understanding and support for families affected by Bronchiolitis. First, examining the long-term psychological and economic impacts on families is essential, particularly how ongoing psychological counseling and financial assistance influence family stress and overall well-being. Quality studies in this area will help establish evidence-based practices for intervention.

Additionally, exploring family-centered care approaches can provide insights into how involving families in care decisions and enhancing communication with healthcare professionals affects their experiences and stress levels.

The design of hospital environments also warrants investigation; specifically, examining how different layouts influence family comfort and interaction could yield valuable insights for creating more supportive spaces. Communication strategies represent another key area for research. Understanding how timely, evidence-based information about Bronchiolitis impacts family engagement and decision-making can lead to improved practices for informing and empowering parents.

Evaluating the effectiveness of post-discharge follow-up programs is crucial to ensure they adequately support families and effectively monitor infant recovery. Research should also assess flexible work policies and their impact on alleviating financial stress and enhancing work-life balance for families. Furthermore, exploring how community resources can assist families, particularly those in remote areas, may offer solutions to logistical challenges and help reduce feelings of isolation.

Evaluating the impact of healthcare professional training on addressing the psychosocial aspects of care can significantly enhance family support. Additionally, developing, and validating measurement tools, including patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), to assess the impact of hospitalization on parents will facilitate the delivery of more tailored support services and improved outcomes. Finally, there is a pressing need for more high-quality studies on complementary and integrative therapies for Bronchiolitis to evaluate their efficacy in reducing anxiety and enhancing the overall experience for both infants and parents. Qualitative studies could provide deeper insights into family experiences and perspectives regarding these therapies, helping to tailor interventions to meet their specific needs.

5. CONCLUSIONS

This narrative review highlights Bronchiolitis hospitalization's significant and enduring impact on infants and their families. Beyond immediate health issues, Bronchiolitis imposes substantial psychological, emotional, social and financial burdens on parents, affecting their overall well-being. Addressing these challenges requires a comprehensive approach that includes enhanced support services, family-centered care, improved hospital environments, and effective communication strategies.

6. PERSONAL VIEW AND AREA OF RESEARCH

The findings of this narrative review underscore the significance of the initiatives undertaken in our General Pediatric Units at the University Hospital of Geneva (HUG) and the ongoing research in this field.

Since 2023, we created the “Salon de Thé Bronchiolite”, a dedicated meeting space for families of Bronchiolitis patients, offering weekly gatherings in a prepared healing environment within our pediatric unit. The primary objective of this initiative was to assess parental satisfaction and understand the impact of Bronchiolitis hospitalization on families through a structured questionnaire. By analyzing insights from these interactions, we aim to identify areas for improvement within our pediatric unit. This approach also benefits healthcare professionals by efficiently disseminating critical information to multiple families while optimizing their time and workload management. Group meetings in these dedicated healing spaces address common concerns, foster empathy and solidarity, and mitigate feelings of isolation among participants. These sessions provide a dynamic learning environment where families can exchange practical tips, thereby enhancing their management of their child's care. After each session, parents complete a French questionnaire designed to evaluate satisfaction and gauge the impacts of bronchiolitis hospitalization. The questionnaire can be filled out during the child's stay and submitted prior to discharge. It features four response options: "definitely not," "I don't think so," "I think so," and "definitely," along with space for additional comments (see Annex 2). Importantly, no personal data is collected, and responses are treated confidentially in accordance with ethical guidelines. Although results have not yet been published, preliminary responses indicate a significant emotional impact on parents during their child's hospitalization, characterized by high levels of worry, stress, and feelings of helplessness. While feelings of guilt and loneliness varied among parents, all expressed increased protectiveness and experienced major disruptions to their personal organization. Parents valued the opportunity to voice their concerns and unanimously found the information provided helpful in alleviating fears and enhancing their understanding of the illness. These findings highlight the critical need for emotional support and effective communication from healthcare providers to better assist parents during their child's hospitalization.

In 2023, we launched the first randomized controlled trial (RCT) in General Pediatrics at HUG, focusing on integrative medicine. This prospective multicenter parallel-group clinical trial aims to assess the efficacy of lavender oil chest wraps as an adjunct to standard care, compared to standard care alone, in reducing cough frequency among infants hospitalized with bronchiolitis. Our secondary objectives include evaluating the reduction in crying episodes and improvements in sleep duration, respiratory distress, oxygen requirements,

length of hospital stay, parental satisfaction with the new treatment, and the impact of bronchiolitis hospitalization on families (Annex 3).(75)

In 2024, we launched a qualitative study exploring the experiences and perspectives of nurses in Geneva and Fribourg involved in the RCT of lavender essential oil chest compresses as a complementary treatment for infants with bronchiolitis. This study seeks to understand nurses' perceptions of the treatment's impact on patients and parents, its influence on their attitudes toward complementary medicine in pediatrics, their satisfaction in caring for bronchiolitis patients, and the specific challenges encountered during implementation. Additionally, the study aims to gather nurses' suggestions for integrating this new treatment into clinical practice.

We believe these initiatives could offer physicians and parents a novel and cost-effective treatment option while contributing to family-centered care. By involving parents as partners in the implementation of therapies, we aim to strengthen the parent-child bond, providing long-term benefits for the upbringing of children.

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“If a little girl wants to fly, we don’t say ‘children don’t fly’. Instead, we pick her up and carry her around above our heads... so she feels she has flown there.”

D. W. Winnicott

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8. ANNEX:

Annex 1: Summary of Studies Included in this Narrative Review:

Author(s)	Article Type	Study Aim	Population Studied	Sample Size	Impact on Infants	Impact on Families
Van Benthum (2022) (59)	Prospective Cohort Study	To evaluate the psychological impact on parents of children admitted to PICU for Bronchiolitis	Parents/care givers of children with bronchiolitis in the PICU at Radboudumc Hospital, a tertiary facility in the Netherlands	33 out of 42 eligible families (78.6% response rate)	No direct infant impact reported	Psychological distress, including PTSD, anxiety, and depression. Key risk factors include prior psychological issues and perceived disease severity
Robbins (2006) (52)	Prospective Cohort Study	To examine the at-home recovery of infants post-hospitalization for Bronchiolitis	Otherwise healthy infants under 1 year of age admitted with Bronchiolitis to 6 children's hospitals in US	Telephone interviews with 486 parents out of 570 eligible (85%)	Delayed recovery is associated with ongoing symptoms like coughing and wheezing. Difficulties with Normal Routines: feeding/sleeping	Increased stress levels, time off work, and disruption to family routines
Campbell (2020) (51)	Qualitative Study	To explore parents' experiences with Bronchiolitis	Parents of children admitted to the Stollery Children's Hospital emergency department with bronchiolitis	15 parents	Parents reported their child experiencing a loss of energy, appetite, and seeming generally uncomfortable	Significant emotional and financial strain, that and impacts the entire family's life.; parents felt unprepared
Lapillonne (2013) (53)	Multicenter Longitudinal Observational Study	To develop and validate the Impact of Bronchiolitis Hospitalization Questionnaire (IBHQ©)	Parents of infants under one year old hospitalized for Bronchiolitis in France	707 completed questionnaires (368 discharge and 339 follow-up questionnaires) from 463 eligible infants	Parents were more protective, which reduced severity. Infants faced disrupted breastfeeding, increased crying, and weight loss.	The IBHQ measures the multifaceted impact of an infant's hospitalization for bronchiolitis on parents, including lasting organizational, emotional, and physical effects

Author(s)	Article Type	Study Aim	Population Studied	Sample Size	Impact on Infants	Impact on Families
Lapillonne (2012) (28)	Multicenter Longitudinal Study	To explore the impact of Bronchiolitis hospitalization on parents across different infant groups	Parents of infants under one year hospitalized for bronchiolitis across 77 hospitals in France: 332 full-term, 71 preterm, 60 very preterm, 28 with CHD	Parents of 463 eligible infants completed a total of 368 discharge and 339 follow-up questionnaires, with 315 completed for both (IBHQ)	No direct impact on infants reported	Distress, fear for the future, guilt, and disruption of daily organization. Psychological and emotional burdens persisted or increased over time
Carbonell-Estrany (2018) (61)	Observational Study	To understand parental distress during RSV hospitalization and its relation to communication with healthcare professionals	Parents of children under 24 months hospitalized for RSV infection, along with healthcare professionals, in Spain and Italy	Initial Meetings: 24 parents and 11 healthcare professionals; Survey completed by: 105 parents and 56 healthcare professionals	No direct infant impact reported	Parental distress increased, especially in the Spanish cohort, due to concerns over infection risks, readmission fears, and confidence in healthcare provider communication and competence
Custovic (2024) (65)	Cross-Sectional Survey	To assess parents' views on the link between RSV infection, wheezing-related healthcare needs, resource use, and daily family impact	Parents of children ≤6y from the US, UK, Spain, and Italy, including RSV-diagnosed and non-RSV groups	1200 parents (300 per country)	Children with RSV history show increased wheezing severity and frequency, affecting sleep, emotional well-being, and physical activity	Emotional and financial impact, particularly in the UK and Italy, affecting daily activities and social life
Peeler (2011) (63)	Phenomenological Study	To examine the experiences of parents and nurses dealing with infants requiring oxygen therapy for severe Bronchiolitis	Mothers and nurses caring for infants hospitalized with severe Bronchiolitis in Australia	24 participants (12 mothers, 12 nurses)	Significant distress with headbox as it interfered parent-child interaction	Intense fear for her child's life, compounded by emotional distress from isolation and discomfort associated with various oxygen delivery methods

Author(s)	Article Type	Study Aim	Population Studied	Sample Size	Impact on Infants	Impact on Families
van Dijk (2023) (56)	Prospective Cohort Study	To evaluate HRQoL in children six months post-PICU admission for Bronchiolitis	Children admitted to PICO with Bronchiolitis (mean age of 7.6 months (SD 2.5 months). Parents were assessed six months after PICU discharge in the Netherlands	34 children with a response rate of 81%	Impairments in physical functioning and general health domains (Scores on lung and stomach issues compared to the normative group)	It increased parental stress related to the child's ongoing health issues
Spuijbroek (2011) (57)	Observational Study	To assess ITQOL responsiveness across five conditions, parents evaluated their child's health 2–6 months post-hospitalization	Children with five health conditions, including bronchiolitis, compared to a healthy control group in the Netherlands	47 patients admitted to the hospital for RSV bronchiolitis (parents response rate 66%)	Significant impact on physical functioning and general health perceptions in children with RSV	Lower in parental emotional and parental time impact
Leidy (2005) (58)	Prospective Study	To quantify distress levels in children, caregivers, and families related to severe RSV hospitalization and the recovery period	RSV-infected children under 30 months of age, with a history of prematurity (gestational age <35 weeks) at five hospitals in US	91 children (46 RSV-infected children and 45 age-matched controls) and their caregivers	Caregivers rated children's overall health and functional status as significantly poorer	Increased caregiver stress and compromised personal and family health persisted for up to 60 days post-discharge
Wrotek (2023) (62)	Prospective Survey Study	To assess QoL in children hospitalized with laboratory-confirmed RSV	Children under 2 years of age hospitalized due to laboratory-confirmed RSV infection at the Bielanski Hospital, Warsaw	132 children	Lower QoL in infants post-hospitalization	Impact not directly assessed

Author(s)	Article Type	Study Aim	Population Studied	Sample Size	Impact on Infants	Impact on Families
Wrotek (2023) (29)	Prospective Survey Study	To estimate parental QoL loss due to RSV hospitalization	132 caregivers of children under 2 years of age hospitalized due to laboratory-confirmed RSV infection at the Bielanski Hospital, War saw	132 caregivers	Impact not directly assessed	Caregivers' QoL is impacted by RSV hospitalization, with anxiety and depression as the most common issues
Rolfsjord (2015) (55)	Multicenter Randomized Clinical Trial	To assess examined the impact of bronchiolitis and common early asthma risk factors on later QoL (9 months later)	Parents of infants (mean age 4 months, range 0–11 months) hospitalized for acute bronchiolitis, along with controls, from eight counties in Norway's South-East Health Region	209 parents of infants hospitalized for acute bronchiolitis, 206 parents of control infants	Lower QoL scores, particularly in overall and general health domains	Impact not directly assessed
Rolfsjord (2016) (50)	Multicenter Randomized Clinical Trial	To evaluate the association between the severity of acute Bronchiolitis and QoL nine months later	Parents of infants (mean age 4 months, range 0–11 months) hospitalized for acute bronchiolitis, along with controls, from eight counties in Norway's South-East Health Region	209 parents of infants hospitalized for acute bronchiolitis; 206 parents of control infants	Severe Bronchiolitis was associated with lower QoL in physical abilities and general health domains	Impact not directly assessed

Author(s)	Article Type	Study Aim	Population Studied	Sample Size	Impact on Infants	Impact on Families
Kopacz (2013) (60)	Qualitative Descriptive Study	To explore the experiences of Alaskan parents with children hospitalized for RSV	Mothers of infants and preschool children hospitalized with RSV in Alaska	Six mothers	Impact not directly assessed	Significant emotional strain includes fear, stress, sleep deprivation, and logistical challenges for remote-area families
Leader (2003) (54)	Cost Analysis Study	To assess the time and out-of-pocket costs associated with RSV hospitalization of infants not prophylaxed against RSV	Parents of infants under 12 months old, born at 33 to 35 weeks gestation, across 10 hospitals in the US	48 parents of premature infants; 34 parents of full-term infants	Impact not directly assessed	RSV hospitalization of preterm infants imposes a significant financial burden, resulting in substantial time and monetary losses that continue after discharge
Pokrzywinski (2019) (64)	Prospective Cohort Study	To evaluate the impact of RSV-confirmed hospitalizations on caregivers of preterm infants	Caregivers of infants under 12 months, born at 29 to 35 weeks' gestation, hospitalized for confirmed RSV across 43 sites in the US	212 parents of preterm infants	Higher infant stress levels and lower health during hospitalization, with improvement one month after discharge	High stress, poor health, and productivity loss at discharge; emotional impact, family disruption, financial, and medical concerns persisted
Díez et. Al (2021) (27)	Observational prospective multicentre surveillance study	To assess the loss of HRQoL and the direct costs associated with an RSV episode	Children under two years and their caregivers in Spain	117 children	Loss in child HRQoL	Loss in caregivers HRQoL and significant healthcare costs associated with Bronchiolitis management

Abbreviations: CHD – Congenital Heart Disease; HRQoL – Health-Related Quality of Life; IBHQ – Impact of Bronchiolitis Hospitalization Questionnaire; ITQOL – Infant/Toddler Quality of Life Questionnaire; PCIU – Pediatric Intensive Care Unit; QoL – Quality of Life; RSV – Respiratory Syncytial Virus; UK – United Kingdom; US – United States

Annex 2: Parent Satisfaction and Impact of Bronchiolitis Hospitalization Questionnaire
(French to English Translation): “*Salon de thé Bronchiolite*”.

Question	Not at all	A little	A lot	Extremely
During this hospitalization, did you feel worried?				
During this hospitalization, did you feel stressed?				
During this hospitalization, did you feel helpless?				
During this hospitalization, did you feel lonely?				
During this hospitalization, did you feel guilty?				
During this hospitalization, did you feel more protective of your child?				
During this hospitalization, did you feel disrupted in your organization?				

Question	Quite dissatisfied	Indifferent or slightly satisfied	Generally satisfied	Very satisfied
What is your level of satisfaction with the encounter?				

Question	Definitely not	I don't think so	I think so	Definitely
Were you able to express yourself?				
Did you receive useful information to reduce your fears about the illness?				
Did you receive useful information to understand your child's illness?				

Annex 3: Impact of bronchiolitis hospitalization questionnaire (RCT lavender):

This questionnaire is already validated in French: Questionnaire IBHQ® - Impact of Bronchiolitis Hospitalization Questionnaire (<https://eprovide.mapi-trust.org/instruments/impact-of-bronchiolitis-hospitalisation-questionnaire>).

Votre vécu lors de la bronchiolite de votre enfant

Questionnaire n°1

(à remplir dans les 7 jours suivant la sortie de l'hôpital)

Avant de commencer à remplir le questionnaire, merci d'inscrire la date d'aujourd'hui

/ _ / _ / / _ / _ / / _ / _ / _ /
 jour mois année

Vous êtes : ☐ Le père de l'enfant hospitalisé pour bronchiolite
 ☐ La mère de l'enfant hospitalisé pour bronchiolite

Madame, Mademoiselle, Monsieur,

Ce questionnaire a été conçu avec des parents d'enfants qui ont été hospitalisés pour une bronchiolite. Il s'intéresse à votre vécu par rapport à cette hospitalisation.

Nous vous remercions de remplir ce questionnaire seul(e) et dans un endroit calme. Prenez tout le temps qui vous sera nécessaire pour répondre.

Si vous ne savez pas très bien comment répondre, choisissez la réponse la plus proche de votre situation ou de celle de votre enfant. Il n'y a pas de réponse "juste" ou "fausse". Si vous ne savez toujours pas répondre à une question, passez à la question suivante.

Les informations contenues dans ce questionnaire sont strictement confidentielles et seront traitées dans le respect de votre anonymat.

Nous vous remercions de votre participation.

1. VOS REACTIONS EMOTIONNELLES LORS DE L'HOSPITALISATION DE VOTRE ENFANT POUR SA BRONCHIOLITE

Les questions suivantes portent sur vos réactions émotionnelles lors de l'hospitalisation de votre enfant pour sa bronchiolite. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux à votre cas :

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, vous êtes-vous senti(e) ... :

	Pas du tout	Un peu	Beaucoup	Enormément
1. inquiet(ète) de ne pas savoir ce qu'il va se passer ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
2. inquiet(ète) de voir votre enfant souffrir ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
3. stressé(e), paniqué(e) ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
4. impuissant(e) ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
5. énervé(e), en colère ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
6. moralement abattu(e) ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
7. moralement effondré(e) ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
8. seul(e) ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
9. coupable qu'il ait eu une bronchiolite ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
10. coupable d'avoir dû le laisser à l'hôpital ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, avez-vous eu les sensations suivantes :

	Pas du tout	Un peu	Beaucoup	Enormément
11. Peur des conséquences de la bronchiolite sur la santé de votre enfant ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

12. Peur que votre enfant ait une nouvelle bronchiolite ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
13. Peur pour la vie de votre enfant ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

2.

LES REACTIONS DE VOTRE ENFANT LORS DE SON HOSPITALISATION POUR SA BRONCHIOLITE

Les questions suivantes portent sur les réactions de votre enfant lors de son hospitalisation pour sa bronchiolite. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux au cas de votre enfant :

Lors de son hospitalisation pour sa bronchiolite, votre enfant a-t-il... :

	Je ne sais pas	Pas du tout	Un peu	Beaucoup	Enormément
14. été grognon ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
15. été souvent en pleurs ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
16. été crispé, tendu ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
17. été agité ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
18. été sans réaction ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
19. été perturbé dans la prise de ses repas ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
20. perdu l'appétit ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
21. perdu du poids ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃

VOS REACTIONS PHYSIQUES LORS DE L'HOSPITALISATION DE VOTRE ENFANT POUR SA BRONCHIOLITE

Les questions suivantes portent sur vos réactions physiques lors de l'hospitalisation de votre enfant pour sa bronchiolite. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux à votre cas :

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, ... :

	Pas du tout	Un peu	Beaucoup	Enormément
22. avez-vous été fatigué(e) physiquement ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
23. votre sommeil a-t-il été perturbé ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
24. votre appétit a-t-il été perturbé ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
25. êtes-vous tombé(e) malade ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

26. Si votre enfant est nourri au sein, l'allaitement a-t-il été perturbé lors de son hospitalisation ?

☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
Il n'est pas nourri au sein	Pas du tout	Un peu	Beaucoup	Enormément

27. Si votre enfant est nourri au sein, les montées de lait ont-elles été perturbées lors de son hospitalisation ?

☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
Il n'est pas nourri au sein	Pas du tout	Un peu	Beaucoup	Enormément

VOTRE ORGANISATION AU QUOTIDIEN LORS DE L'HOSPITALISATION DE VOTRE ENFANT POUR SA BRONCHIOLITE

Nous souhaiterions savoir dans quelle mesure l'hospitalisation de votre enfant pour sa bronchiolite a perturbé votre quotidien. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux à votre cas :

L'hospitalisation de votre enfant pour sa bronchiolite a-t-elle perturbé :

	Pas du tout	5.	Un peu	Beaucoup	Enormément
28. vos habitudes de repas ?	☐ ₀		☐ ₁	☐ ₂	☐ ₃
29. l'organisation de vos nuits (dormir à l'hôpital,...) ?	☐ ₀		☐ ₁	☐ ₂	☐ ₃
30. l'organisation de vos tâches domestiques (les courses, le ménage, ...) ?	☐ ₀		☐ ₁	☐ ₂	☐ ₃
31. l'organisation de votre vie familiale ?	☐ ₀		☐ ₁	☐ ₂	☐ ₃
32. l'organisation de vos activités de loisirs habituelles (voir des amis, aller au cinéma, vous promener, ...) ?	☐ ₀		☐ ₁	☐ ₂	☐ ₃

33. L'hospitalisation de votre enfant pour sa bronchiolite a-t-elle perturbé l'organisation de votre travail ?

☐₉ ☐₀ ☐₁ ☐₂ ☐₃
 Je ne travaille pas Pas du tout Un peu Beaucoup Enormément

34. Lors de l'hospitalisation de votre enfant pour sa bronchiolite, votre organisation quotidienne a-t-elle été perturbée par vos déplacements vers l'hôpital ?

☐₀ ☐₁ ☐₂ ☐₃
 Pas du tout Un peu Beaucoup Enormément

6.

LES REACTIONS DES FRERES ET SOEURS LORS DE L'HOSPITALISATION DE VOTRE ENFANT POUR SA BRONCHIOLITE
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S1. Votre enfant a-t-il des frères et soeurs ?

☐₁ Oui

☐₀ Non

↳ Si non, passez directement à la question 37.

Les questions suivantes portent sur les réactions des frères et soeurs lors de l'hospitalisation de votre enfant. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux au cas de vos enfants :

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, selon vous, ses frères et soeurs ont-ils... :

	Je ne sais pas	Pas du tout	Un peu	Beaucoup	Enormément
35. été tristes à cause de l'absence de votre enfant ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
36. été inquiets au sujet de votre enfant ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃
37. été tristes à cause de votre absence ?	☐ ₉	☐ ₀	☐ ₁	☐ ₂	☐ ₃

VOTRE ATTITUDE FACE A VOS ENFANTS LORS DE L'HOSPITALISATION POUR LA BRONCHIOLITE

Les questions suivantes portent sur votre attitude face à vos enfants lors de l'hospitalisation pour la bronchiolite. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux à votre cas :

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, ... :

	Pas du tout	Un peu	Beaucoup	Enormément
38. avez-vous été plus attentif(ve) avec lui ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
39. avez-vous été plus protecteur(trice) avec lui ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
40. avez-vous été moins sévère avec lui ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

S2. Avez-vous d'autres enfants ?

☐₁ Oui

☐₀ Non

↳ Si non, passez directement à la question 43.

Lors de l'hospitalisation de votre enfant pour sa bronchiolite, ... :

	Pas du tout	Un peu	Beaucoup	Enormément
41. avez-vous été préoccupé(e) au sujet de la garde de vos autres enfants ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
42. avez-vous eu l'impression de moins vous occuper de vos autres enfants ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃
43. avez-vous dû cacher votre inquiétude devant vos autres enfants ?	☐ ₀	☐ ₁	☐ ₂	☐ ₃

LES CONSEQUENCES FINANCIERES DE L'HOSPITALISATION DE VOTRE ENFANT POUR SA BRONCHIOLITE

Les questions suivantes portent sur les conséquences financières de l'hospitalisation de votre enfant pour sa bronchiolite. Pour chacune des questions, veuillez cocher la case qui s'applique le mieux à votre cas :

44. Lors de l'hospitalisation de votre enfant pour sa bronchiolite, avez-vous eu plus de dépenses (frais médicaux, frais de déplacements, frais de garde...) ?

☐₀

Pas du tout

☐₁

Un peu

☐₂

Beaucoup

☐₃

Enormément

45. Lors de l'hospitalisation de votre enfant pour sa bronchiolite, avez-vous eu moins de revenus (jours non travaillés) ?

☐₉

Je ne travaille pas

☐₀

Pas du tout

☐₁

Un peu

☐₂

Beaucoup

☐₃

Enormément

46. Lors de l'hospitalisation de votre enfant pour sa bronchiolite, ces problèmes d'argent ont-ils perturbé votre vie familiale ?

☐₀

Pas du tout

☐₁

Un peu

☐₂

Beaucoup

☐₃

Enormément

QUESTION GENERALE

S3. Avez-vous rempli ce questionnaire seul(e) ou avec votre conjoint(e) ?

☐₀

Seul(e)

☐₁

Avec mon conjoint(e)