

The Indirect Impact of RSV

RSV PARENT & PROVIDER SURVEY RESULTS





Executive Summary

RSV, or respiratory syncytial virus, is a common, highly contagious seasonal virus that affects 97% of children by the age of 2.¹ Yet despite RSV being common among young children, most parents know little about it.

RSV is the leading cause of hospitalization for babies less than a year old, and nearly 58,000 infants and young children are hospitalized for RSV each year. This dangerous virus doesn't just impact preemies — it affects all babies and young children.² In fact, it's also the leading cause of bronchiolitis and pneumonia in children under one. And it can carry significant financial, emotional and social burdens for patients' families.

Now, national survey data from the Alliance for Patient Access and the National Coalition for Infant Health highlight the experiences and opinions of two critical demographics — parents whose babies or children had RSV, and health care providers who take care of babies and children with RSV. Taken together, these surveys offer a glimpse of awareness, successes and ongoing challenges related to RSV. The findings also identify goals that stakeholders and policymakers can pursue going forward.

Parents Struggle as their Child Suffers with RSV

Hospitalization for RSV is not uncommon. Of the 340 surveyed parents:



67% reported that their child was **hospitalized** for RSV.

The burden of RSV goes well beyond the physical impact on babies and young children.



69% of parents felt **guilty** they could not do more to prevent their child's experience with RSV.



68% of parents said watching their child suffer **affected their mental health**.



More than 1/3 of parents said the burden of RSV placed a **strain on their relationship** with their partner.

Following their child's recovery, parents had to face the medical bills that followed.



More than 2/3 of parents said that RSV also **presented their family with a financial burden** or financial crisis.

Providers Support Families

Health care providers also shoulder the burden of RSV.



48% of providers said they found it **difficult to decide** whether to send a young RSV patient to the emergency room.

RSV Awareness Lags

Despite the prevalence of RSV, parents' responses emphasize there is a need for greater knowledge of RSV.



43% of RSV patients' parents **"had never heard of RSV"** before their child was sick."

Preventive Immunizations are on the Horizon

Parents and providers all expressed a **desire to see immunizations and other preventions in the future.**

Up-and-coming preventions will improve care and help prevent the burden from harming infants, young children and their families.



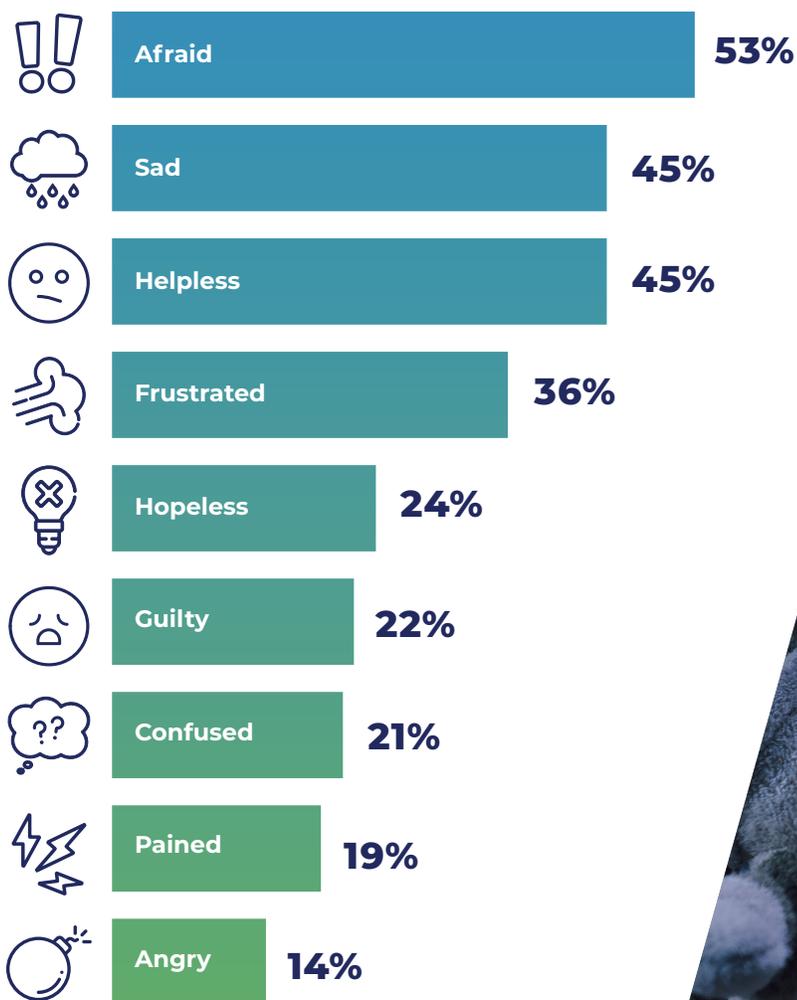
RSV's All- Encompassing Burden

The Emotional Toll

It's never easy for parents to see their children suffer. But RSV can leave parents particularly traumatized.



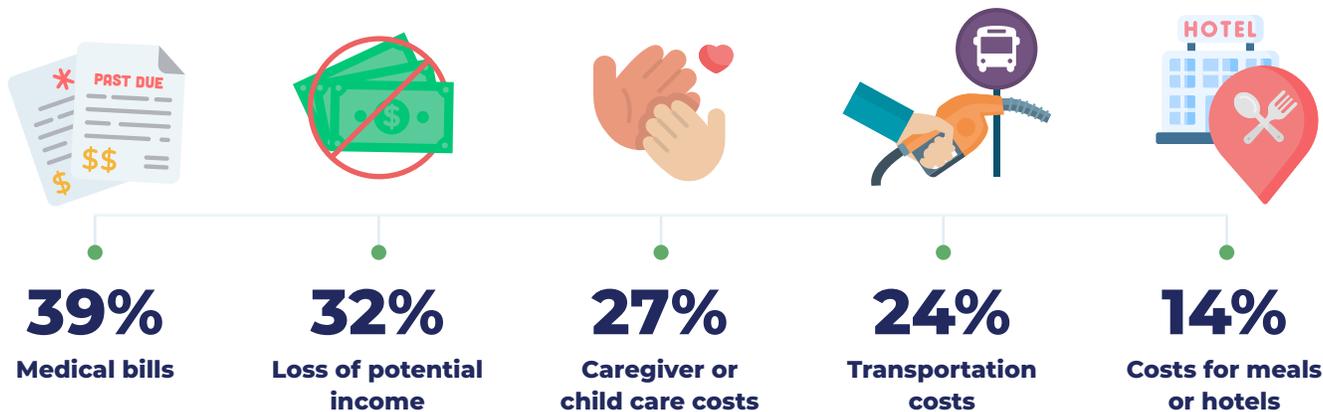
In total, surveyed parents described their feelings throughout their child's illness:



The Financial Burden

More than two-thirds of parents said that RSV also presented their family with a **financial burden** or **financial crisis**.

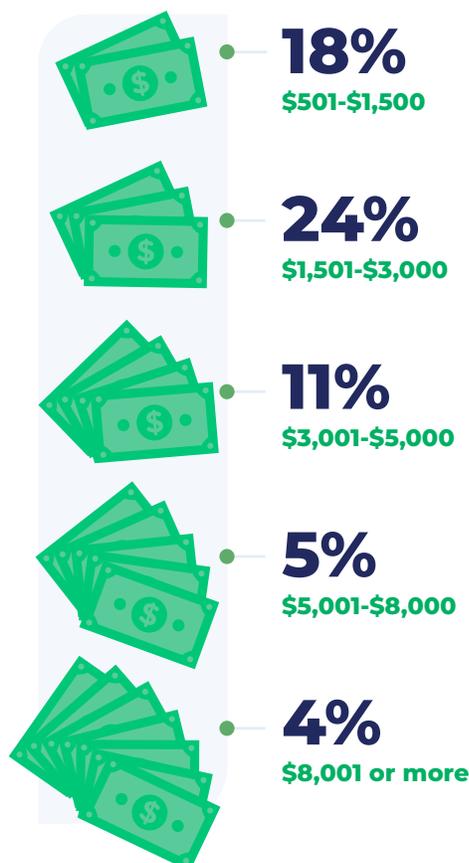
The RSV-related financial challenges that parents reported included:



Additionally, parents reported that their child's illness impacted their ability to work, which for many resulted in a loss of income.



The bottom-line costs of a child's RSV experience represent a significant expense for most families, and a financial crisis for many. Families estimated their total related costs to be:



The Social Burden

Caring for a young child suffering from RSV often requires help from people outside of the immediate family. In addition to the steep medical costs, there is also the time, energy and attention taken from other aspects of parents' lives.



More than 1/2
(54%) had to rely on family members and friends to help with child care, transportation and other responsibilities.



More than 1/3
said the stress put a strain on their relationship with their partner.

Siblings felt the strain, too.



42%
of parents said they struggled to care for their other children when one had RSV.

42%
said their other children were distressed watching their sibling struggle with RSV.

41%
said RSV prevented patients' siblings from participating in extracurricular activities or playing with friends.





Caring for Babies and Children with RSV

Tough Calls for Health Care Providers

Because there is no treatment for RSV beyond supportive care, health care providers struggle with decisions about testing and hospitalization.



Almost half

(48%) found it difficult to decide whether to send a young RSV patient to the **emergency room**.

Nearly $\frac{1}{3}$

of providers have been **reluctant to test for RSV** in the past because the only treatment option is supportive care — and half said their coworkers have expressed reluctance to test because of supportive care being the only course of treatment.

Typical RSV Timelines

According to parents, the most common age for RSV diagnoses was between 7 and 12 months.

The most common duration of the illness was 4-6 days, during which time the vast majority of parents (89%) took their child to see a medical professional between one and three times.



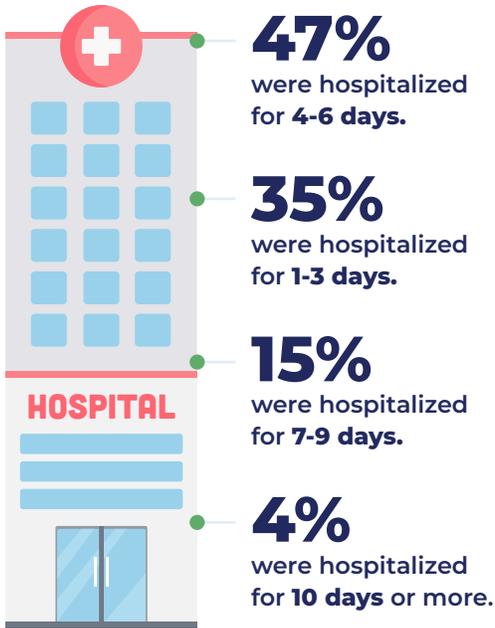
89%

of parents **took their child to see a medical professional** between one and three times.

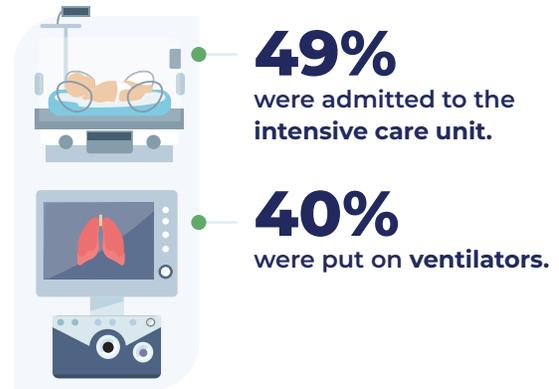


Hospital Stays and Treatments

Of the 340 surveyed parents, 230 had their children hospitalized for RSV. Of these cases:



And during their hospitalizations:



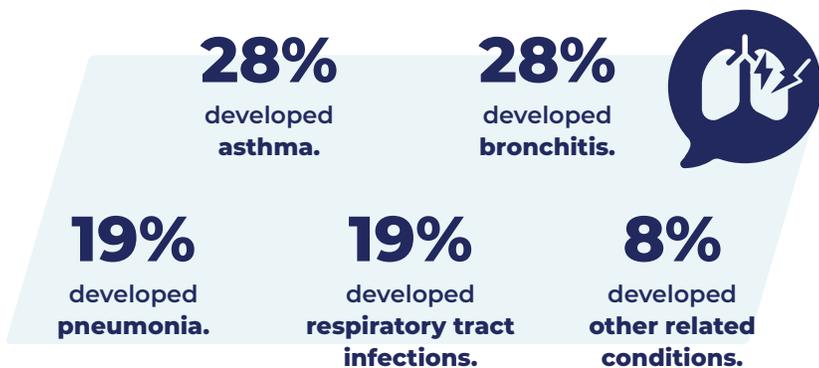
When asked about treatments their children were administered in the hospital, parents answered "oxygen" most often.



Even Afterward, Respiratory Risks Remain

Even after RSV subsides, young patients continue to face heightened risks for other respiratory conditions. RSV is the leading cause of bronchiolitis and pneumonia among infants, and it increases patients' long-term risks of developing asthma.³

According to the surveyed parents, their children who recovered from RSV still faced additional health challenges:





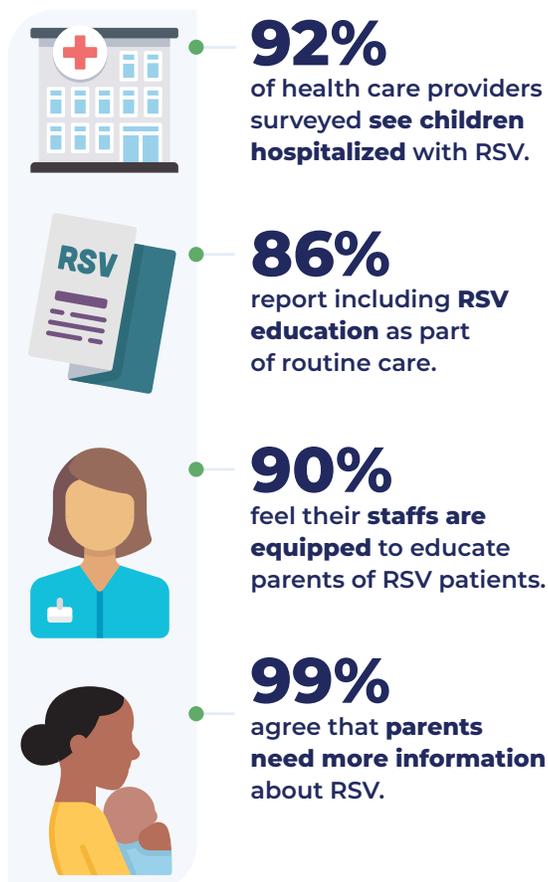
Understanding the Virus

The RSV Awareness Gap

Though almost all children contract RSV at least once by their second birthday, most parents are unaware of the disease until their own child is diagnosed.



This awareness gap persists despite health care providers' regular encounters with the disease.



Not Just a Premie Problem

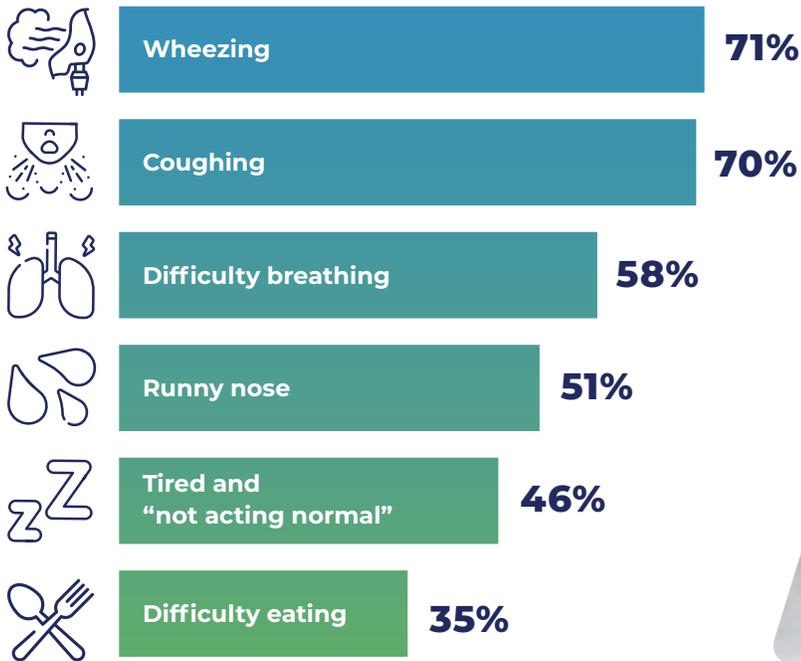
Health care providers emphasize that **all children are at risk for serious RSV disease.**



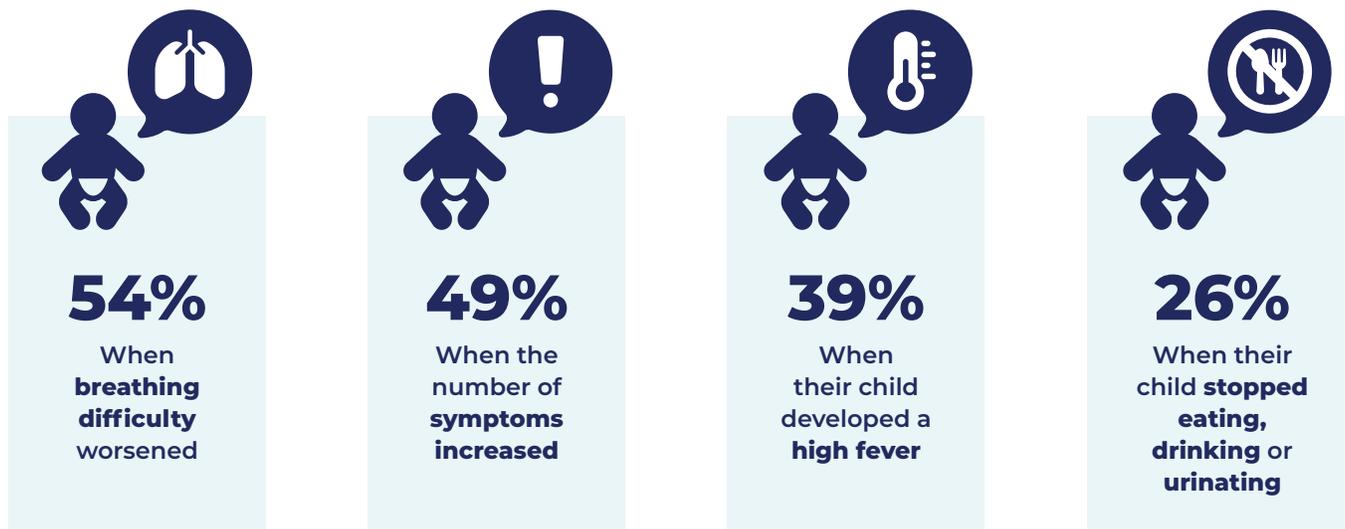
More than half of providers stated that **at least 50%** or more of the babies they see hospitalized for RSV had been **born full term** and didn't have preexisting conditions.

What Symptoms Send RSV Patients to the Doctor?

Parents overwhelmingly reported that their kids' RSV symptoms mimicked those of a cold or flu:



Most parents decided to seek professional medical care when their children's symptoms multiplied or intensified. Parents decided to take their child to a doctor:





The Future of RSV Prevention & Treatment

Providers' Engagement with Patients and Parents

Parents and health care providers were aligned on strategies for fighting RSV now and in the future.

96%



of parents said they **trust their pediatrician** to consider their input while making treatment decisions for their child.

96%



of health care providers agree that they are **responsible for educating parents about RSV**, and 95% of parents agree RSV education should be a routine part of pediatric care.



Health care providers unanimously agree that they have a duty to **stay informed about RSV treatments (100%)** and about RSV's spread in their community (99%).

Policy Recommendations

Health care providers and parents overwhelmingly support greater awareness and improved options to prevent and treat RSV.



97%

of providers said **immunizations and vaccine-like interventions** could help minimize the burden of RSV.



92%

agreed that, if an immunization were available, it should be **added to the Vaccines for Children program's list** of pediatric vaccines.



92%

agreed that **policy should ensure all babies and children get access** to future immunizations or preventive interventions for RSV.



Expert Survey Analysis



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THE METHODOLOGY

Utilizing “YouGov,” a global public opinion and data company, the sample for the study was recruited from a pre-recruited selection of parents who had opted in to YouGov’s platform and panel of U.S. physicians. All responses were collected through YouGov’s survey platform. The platform utilized an opt-in panel, and sample participants had given prior consent to be contacted for surveys. Respondents to the survey were invited to the study by e-mail invitation. Providers were previously pre-profiled, and their specialty was confirmed and their treatment of babies and children with RSV. Parents were screened in a similar manner, looking for those who had had at least one child with RSV illness.

After completing the study, qualified respondents were compensated with an honorarium.

DISCUSSION AND IMPLICATIONS

While this survey was conducted in conjunction with a market research firm using a convenience sampling methodology, the data further validates the several areas of concern related to RSV disease burden and impact on families and the health care system. The impact of social determinants of health (SDOH) on the mother/baby dyad are well documented. The impact of low socioeconomic status, low maternal education, poverty, food insecurity, obesity, housing and transportation issues are well documented.

This sample of parents had significant emotional, social, and financial impact from their child(ren) having RSV. Yet, based on the limited demographic data collected, one could argue that most of them do not suffer from multiple SDOH. RSV disease burden on parents and families can be anticipated to be more profound for parents that have to navigate/overcome the presence of multiple SDOH.

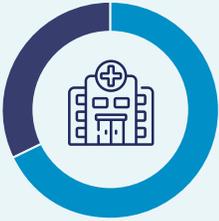
The severity of RSV disease reported in this survey was an unexpected finding. While specific birth gestation and chronological age data was not collected, parents did report hospitalizations of 7 or more days (20%) and of those children (all ages) who were hospitalized, 49% required ICU care and almost all in the ICU required mechanical ventilation (40% of those in the ICU).

Parents and the public need more evidenced-based information about RSV. The health care and public health communities must rally to disseminate information related to RSV prevention and early diagnosis so that the public knows just as much about RSV as they do influenza. But this responsibility cannot be solely on neonatal and pediatric providers. As new preventive immunizations are trialed and receive FDA approval, obstetrical and women’s health providers will play a key role, as will public health nurses and local health departments across the country. While this survey was focused on the impact of RSV disease burden in children and their families, it is important to note that RSV also significantly impacts the geriatric population and is a significant contributor to respiratory morbidity and mortality in older adults.

Survey Details

PARENTS SURVEY

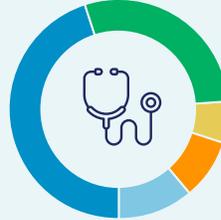
340 parents of at least one child with RSV



67% had at least one child hospitalized for RSV

PROVIDERS SURVEY

175 total providers interviewed



29% Pediatricians
45% Pediatric NP or PA
11% Neonatologist
9% Neonatal NP or PA
6% Pediatric respirologist



67% worked in an outpatient facility
33% worked in a hospital

References

1. <https://www.lung.org/blog/about-rsv-and-infants> "RSV and Infants: a Respiratory Disease That Can Be Deadly." American Lung Association. October 20, 2021.
2. <https://www.cdc.gov/rsv/research/us-surveillance.html> Ibid. ("RSV Trends and Surveillance." Centers for Disease Control and Prevention.)
3. <https://www.contemporarypediatrics.com/view/there-link-between-rsv-and-asthma-development> "Is there a link between RSV and asthma development?" Rachel Zimlich, RN, BSN. *Contemporary Pediatrics*, September 3, 2019.



Alliance for Patient Access

The Alliance for Patient Access is a national network of policy-minded health care providers advocating for patient-centered care.

AllianceforPatientAccess.org



NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

The National Coalition for Infant Health educates and advocates on behalf of infants from birth to age two.

InfantHealth.org

