

ResQ Family Study

Impact of **Res**piratory Syncytial Virus (RSV) Hospitalisation on **Q**uality of Life of **Families** – A Multi-Country Study

PROJECT REPORT



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EXECUTIVE SUMMARY

*It's almost 2 years ago now, but Barbara Plagg remembers it as though it happened yesterday. She was in an emergency room in a hospital in Bolzano, Italy and watched as doctors rushed to save her 3-week-old baby girl. “**The breathing aid in your baby’s little nose, the needle in the tiny hand and your heart as mum is breaking**”, she recalls this painful memory. Shortly afterwards, she was informed that her little daughter had contracted the Respiratory Syncytial Virus (RSV).*

The human **Respiratory Syncytial Virus (RSV)** is a global cause of hospitalisations in early childhood with approximately 33 million cases of acute lower respiratory tract infections in children younger than 5 years¹. Even though the course of the disease is unpredictable, in particular for newborns, the first infection may cause severe bronchiolitis that can sometimes be fatal requiring (invasive) supportive care measures such as supplemental oxygen, fluid replacement or mechanical ventilation. Since family life suddenly changes, in particular with an infant’s hospitalisation, **RSV usually affects the entire family** in myriad of ways. However, until today, there is only little evidence available on how a severe infection and hospitalisation in infants affects family life in a holistic way. Therefore, the results of EFCNI’s **ResQ Family study** (ResQ Family: Impact of Respiratory Syncytial Virus hospitalisation on Quality of life of Families – a multi-country study) aim to shed light on existing knowledge gaps and specifically emphasise the caregiver perspective by investigating parental health-related quality of life and related dimensions in **four European countries** (France, Germany, Italy and Sweden). A detailed description on how the study was developed can be found in the corresponding and publicly accessible [study protocol](#)². By taking a parent perspective, this research was specifically dedicated to their burden and challenges during the infection and hospitalisation of their infant. With the use of an online survey conducted during the 2022/2023 RSV season, **a total of 138 parents** were recruited and shared their stories.

The results of this project report are based on a corresponding [research article](#)³ which provides a comprehensive overview of the overall and country-specific situation related to a wide range of RSV-related symptoms but also emotions, physical and mental dimensions occurring to families in this challenging situation during the acute infection phase.

Each year during the colder months, the RSV season is an unpredictable challenge for both healthcare professionals and affected families, with a lack of knowledge on the full impact on families and the healthcare system. Identifying potential stressors can be helpful to understand the needs and worries of parents, raise awareness among all relevant stakeholders and finally improve the situation for the individual patient, its environment and the general public.

1 Li, Y.; Wang, X.; Blau, D.M.; Caballero, M.T.; Feikin, D.R.; Gill, C.J.; Madhi, S.A.; Omer, S.B.; Simões, E.A.; Campbell, H.; et al. Global, Regional, and National Disease Burden Estimates of Acute Lower Respiratory Infections Due to Respiratory Syncytial Virus in Children Younger than 5 Years in 2019: A Systematic Analysis. *Lancet* 2022, 399, 2047–2064.

2 Trautmannsberger I, Bösl S, Tischer C, Kostenzer J, Mader S, Zimmermann LJ, The ResQ Family Study Group. ResQ Family: Respiratory Syncytial Virus (RSV) Infection in Infants and Quality of Life of Families-Study Protocol of a Multi-Country Family Cohort Study. *Int J Environ Res Public Health*. 2023 May 23;20(11):5917. doi: 10.3390/ijerph20115917.

3 Trautmannsberger I, Plagg B, Adamek I, Mader S, de Luca D, Esposito S, Silfverdal SA, Zimmermann LJ, Tischer C; ResQ Family study group. The Multifaceted Burden of Respiratory Syncytial Virus (RSV) Infections in Young Children on the Family: A European Study. *Infect Dis Ther*. 2024 May 20. doi: 10.1007/s40121-024-00989-0. Epub ahead of print. PMID: 38767780.



Just breathe! PARENT'S VOICES

"[...] You feel [...] sad and angry too, to have to divide ourselves between our two children, to say goodbye to one and say hello to the other [...] What kept us going was the unwavering support of our family to look after the big brother, prepare food etc. as well as our very strong relationship as a couple and the extraordinary involvement of the father. The hardest part was really the separation from the family and the lack of a home."

French mother of a term born infant hospitalised with 36 days of age

"A stressful time, with a long period of illness. Seeing the children so ill was the worst thing for me. I hardly dared to sleep at night during the worst phase. Only when we were in the hospital and I knew that if something was wrong, the doctors and nurse would be informed directly via the oxygen monitoring system, could I relax a little. When the children started to feel better, I felt a great sense of relief."

German mother of a term born infant hospitalised with 95 days of age

"[...] The fear is great and especially the sense of helplessness. Personally, the thing that helped me realise that I had to rush to the hospital were the videos and information I searched for on the Internet [...] One piece of advice I would give to parents is to always follow their instincts."

Italian mother of a term born infant hospitalised with 47 days of age

"[...] I am already very exhausted and ending up in a new stressful situation makes me both angry and sad. I am a single parent and already traumatised from 4 months in the neonatal unit from my son's birth. It is hard to see him go through this again [...]. Today I am most afraid that he will get sick again this season and what can I do? Do I need to quit my job to be with him at home?"

Swedish (single) father of an extremely preterm born infant hospitalised with 16 months of age

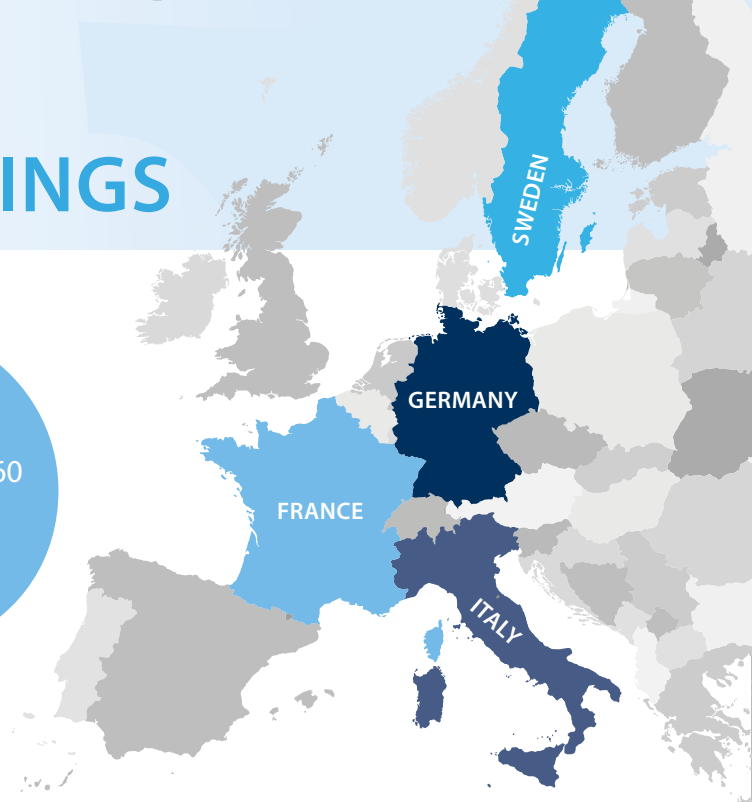
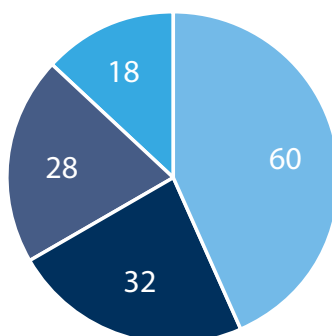




OVERALL KEY FINDINGS

TOTAL SET OF RESPONDENTS: 138

	60 France
	32 Germany
	28 Italy
	18 Sweden



STUDY POPULATION AND RSV-RELATED CHARACTERISTICS

	All participants	Country of participants				p-value*
		France	Germany	Italy	Sweden	
Sex caregiver, n (%)	n = 137	n=60	n=32	n=27	n=18	0.0749
Male	8 (5.8)	1 (1.7)	4 (12.5)	1 (3.7)	2 (11.1)	
Female	129 (94.2)	59 (98.3)	28 (87.5)	26 (96.3)	16 (88.9)	
Parental education, n (%)	n = 137	n=60	n=32	n=27	n=18	< 0.001
Never attended school / no graduation / middle school	3 (2.2)	0 (0.0)	2 (6.3)	1 (3.7)	0 (0.0)	
High School / Secondary school certificate	16 (11.7)	2 (3.3)	10 (31.3)	4 (14.8)	0 (0.0)	
College	39 (28.5)	16 (26.7)	8 (25.0)	5 (18.5)	10 (55.6)	
University degree	79 (57.7)	42 (70.0)	12 (37.5)	17 (63.0)	8 (44.4)	
Age child	n=134	n=59	n=32	n=25	n=18	0.817
in months, Median (range)	3 (0-28)	4 (0-23)	3 (0-27)	2 (0-28)	1.5 (0-19)	
Sex child, n (%)	n = 138	n=60	n=32	n=28	n=18	0.6145
Male	77 (55.8)	31 (51.7)	18 (56.3)	16 (57.1)	12 (66.7)	
Female	59 (42.8)	28 (46.7)	14 (43.8)	12 (42.9)	5 (27.8)	
Not specified	2 (1.4)	1 (1.7)	0 (0.0)	0 (0.0)	1 (5.6)	
Gestational age, n (%)	n = 138	n=60	n=32	n=28	n=18	< 0.001
Extremely preterm: less than 28 weeks	6 (4.3)	3 (5.0)	2 (6.3)	0 (0.0)	1 (5.6)	
Very preterm: 28 – < 32 weeks	20 (14.5)	16 (26.7)	4 (12.5)	0 (0.0)	0 (0.0)	
Moderate to late preterm: 32 – < 37 weeks	28 (20.3)	19 (31.7)	2 (6.3)	3 (10.7)	4 (22.2)	
Mature born: ≥ 37 weeks	84 (60.9)	22 (36.7)	24 (75.0)	25 (89.3)	13 (72.2)	
Older siblings living at home with the child, n (%)	n = 138	n=60	n=32	n=28	n=18	0.0022
No	30 (21.7)	22 (36.7)	5 (15.6)	2 (7.1)	1 (5.6)	
Yes	108 (78.3)	38 (63.3)	27 (84.4)	26 (92.9)	17 (94.4)	
Respiratory comorbidities, n (%)	n=136	n=60	n=32	n=26	n=18	< 0.001
No	66 (48.5)	25 (41.7)	25 (78.1)	12 (46.2)	4 (22.2)	
Yes	70 (51.5)	35 (58.3)	7 (21.9)	14 (53.8)	14 (77.8)	
Other comorbidities, n (%)	n=138	n=60	n=32	n=28	n=18	0.6332
No	133 (96.4)	57 (95.0)	30 (93.8)	28 (100.0)	18 (100.0)	
Yes	5 (3.6)	3 (5.0)	2 (6.3)	0 (0.0)	0 (0.0)	



	All participants n	Country of participants				p-value*
		France n	Germany n	Italy n	Sweden n	
Place of diagnosis, n (%)	n=137	n=59	n=32	n=28	n=18	0.0028
In the paediatrician's practice / (other) outpatient practice	28 (20.4)	10 (16.9)	4 (12.5)	13 (46.4)	1 (5.6)	
In the hospital	109 (79.6)	49 (83.1)	28 (87.5)	15 (53.6)	17 (94.4)	
Don't know	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Type of diagnosis, n (%)	n=138	n=60	n=32	n=28	n=18	0.0194
Confirmed diagnosis by test	117 (84.8)	48 (80.0)	31 (96.9)	20 (71.4)	18 (100.0)	
Doctor's diagnosis	19 (13.8)	11 (18.3)	1 (3.1)	7 (25.0)	0 (0.0)	
Don't know	2 (1.4)	1 (1.7)	0 (0.0)	1 (3.6)	0 (0.0)	
Days spent in hospital	n=117	n=55	n=27	n=19	n=16	0.494
Median (range)	6 (1-273)	6 (1-273)	5 (2-62)	7 (2-37)	4 (2-16)	

Note: percentages may not total 100% due to rounding

*p-value <= 0.5 indicates significant differences between the countries

RSV-RELATED SYMPTOMS

Since the onset of RSV related symptoms...



57%

reported that the child presented the symptom "cough" longer than 7 days



33%

reported that the child presented symptoms such as fast breathing and retractions of the chest (dyspnoea) longer than 7 days



Nearly half of the participants (47%)

reported that the child was affected by breathing pauses (apnoea) for at least one or more days



24%

reported that the child presented the symptom "wheezing" longer than 7 days



35%

reported that the child experienced blueness in face and/or lips (cyanosis) for at least one or more days



44%

reported that the child experienced full days without eating for at least one or more days



Nearly two third of the participants (64%)

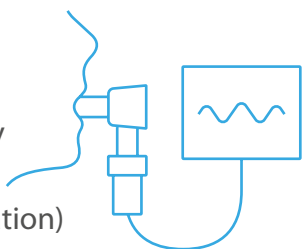
reported that the child was affected by fever for at least one or more days



SUPPORTIVE CARE MEASURES

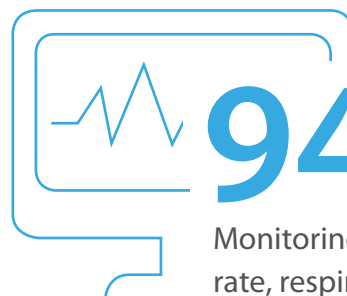
3%

Invasive
respiratory
support
(via intubation)



41%

Tube feeding



94%

Monitoring of heart
rate, respiration and/or
oxygen saturation

80%

Additional oxygen



64%

Non-invasive respiratory
support (e.g. via mask,
nasal prongs)

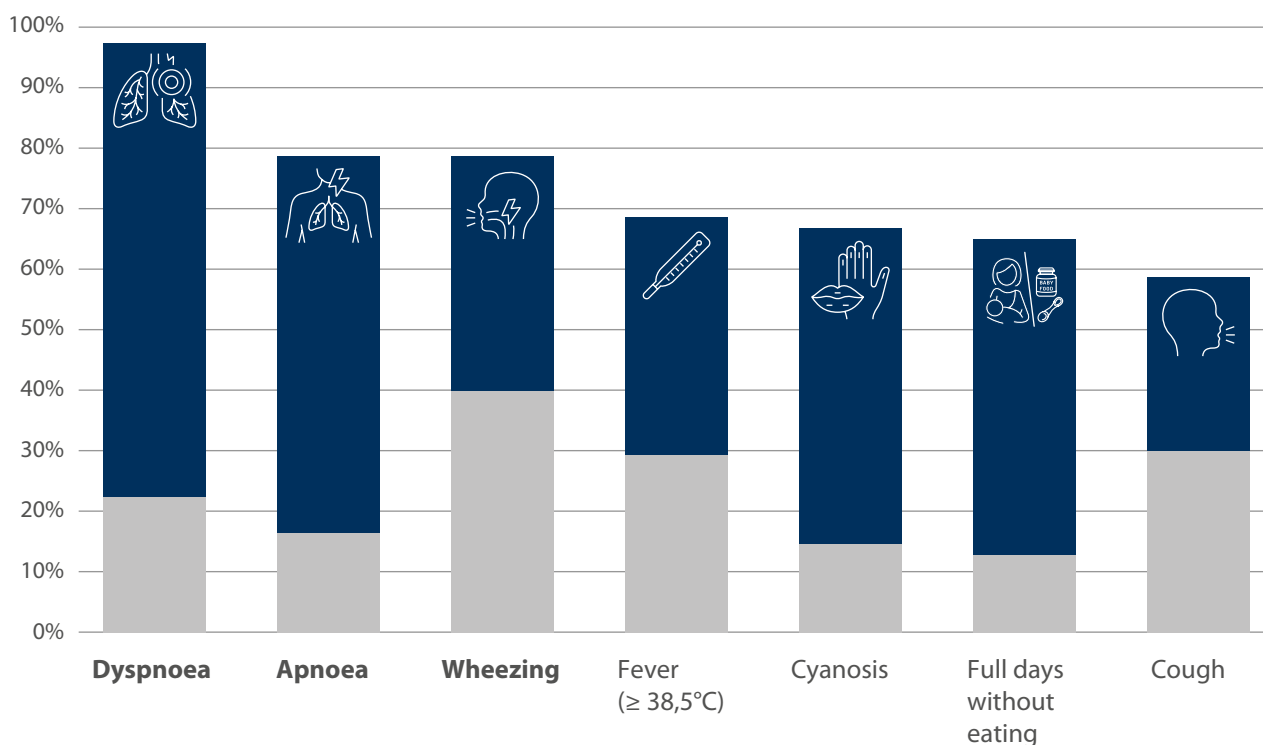
50%

Intravenous fluids
(e.g. infusion)

PARENTAL WORRY ABOUT SYMPTOMS

■ Quite worried

■ Very worried



LOSS OF WORK PRODUCTIVITY



Parents and caregivers have reported missing an **average of 29 hours** from work due to the child's hospitalisation caused by RSV



More than **40%** of all employed participants reported that the child's RSV infection/hospitalisation had a very strong impact on their job productivity



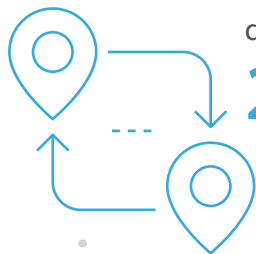
Almost **84%** of all participants reported that the child's RSV infection also affected the professional and/or leisure activities of another family member



My twins were hospitalised at the same time, I stayed with them 24 hours a day [...]. It was very hard for me to manage, my husband could only come for 2 or 3 hours a day because of work. [...]

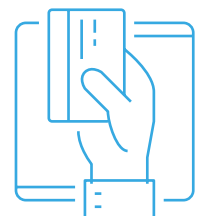
French mother of moderate to late preterm born twins hospitalised with 97 days of age

ADDITIONAL BARRIERS WHEN VISITING THE CHILD IN THE HOSPITAL



distance to the hospital

21%



30%

additional costs (e.g. for travel, accommodation, food)



26%

conflict or overlap with the care of siblings or other family members



PARENTAL HEALTH-RELATED QUALITY OF LIFE AND FAMILY FUNCTIONING

The impact of the infant's RSV-associated hospitalisation on the parental health-related quality of life (HRQoL) was measured with a validated and caregiver-specific questionnaire, the **PedsQL™ Family Impact Module** (PedsQLTM FIM)³. This questionnaire encompasses in total 36 questions and measures the impact on parents' HRQoL during their child's hospitalisation comprising the following categories: **physical functioning** (6 questions), **emotional functioning** (5 questions), **social functioning** (4 questions) and **cognitive functioning** (5 questions), **communication** (3 questions), **worry** (5 questions), **daily activities** (3 questions) and **family relationships** (5 questions).

The following table shows some exemplary questions for the different domains:

Category	Example of question
	each with 5 possible answers from never to almost always
Physical functioning	I feel tired during the day
Emotional functioning	I feel helpless or hopeless
Social functioning	I feel isolated from others
Cognitive functioning	It is hard for me to keep my attention on things
Communication	It is hard for me to talk about my child's health with others
Worry	I worry about how my child's illness is affecting other family members
Daily activities	Difficulty finding time to finish household tasks (see also country-specific results)
Family relationships	Stress or tension between family members (see also country-specific results)

The selected answer to each question was then transformed into a score from **0-100** with Never = 100 | Almost never = 75 | Sometimes = 50 | Often = 25 | Almost always = 0.

In addition, average scores were calculated for

- All questions, named the **Total Score**
- Questions from physical, emotional, social, and cognitive functioning categories, named the **Parent HRQoL Summary Score**
- Questions from the daily activities and family relationships categories, named the **Family functioning Summary Score**

With all scores: the higher the score, the higher the HRQoL or family functioning and the less the perceived impact of the RSV infection on the parent's quality of life.

Average PedsQL FIM scores from a community sample of **healthy children** (Ø) serve as "standard or reference values" and can be used for a comparison with our results⁴:



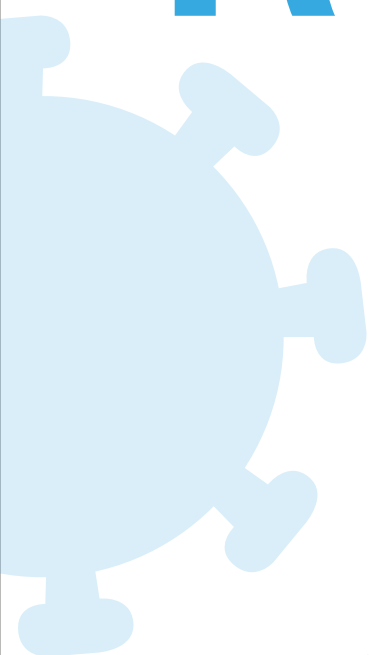
³ Varni J.W., Sherman S.A., Burwinkle T.M., Dickinson P.E., Dixon P. The PedsQLTM Family Impact Module: Preliminary Reliability and Validity. Health Qual. Life Outcomes. 2004;2:55. doi: 10.1186/1477-7525-2-55.

⁴ Medrano G.R., Berlin K.S., Hobart Davies W. Utility of the PedsQLTM Family Impact Module: Assessing the Psychometric Properties in a Community Sample. Qual Life Res. 2013;22:2899–2907. doi: 10.1007/s11136-013-0422-9.



PARENTS' EXPERIENCES –

COUNTRY-SPECIFIC RESULTS



FRANCE

More than half of the participants

57%

felt often or always **guilty** for not having prevented the RSV infection of their child



FEELINGS IN RELATION TO THE CHILD'S HEALTH STATUS DURING HOSPITALISATION

83%

felt often or always **stressed** about their child's health status

68%

Over 2/3 of the participants experienced constant **guilt** about being separated from other family members, such as other children or their partner

„I was very stressed and sad not to see my other child who was at home. I was very upset not to be with all the children, I was at my worst. [...] I felt bad for not having been able to protect my child from going out too much? House not humidified enough? Nose wash not frequent enough? Many questions in my mind.“

French mother of a moderate to late preterm born infant, hospitalised with 4 days of age

90%

stated that they experienced the feeling of **loneliness** always, often or at least sometimes



PARENTAL HEALTH-RELATED QUALITY OF LIFE AND FAMILY FUNCTIONING

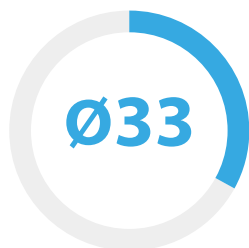


All scores are ranging from 0-100, with higher scores standing for better functioning in each dimension and summary scores and thus less perceived impact of the RSV infection on the parents' HRQoL or family functioning.



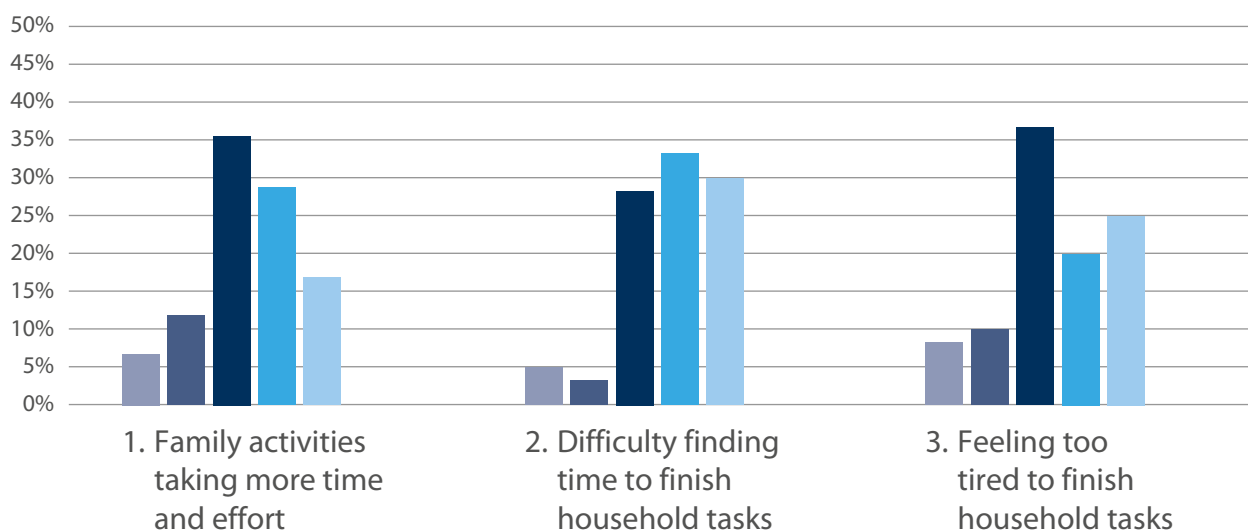
With an average of 33 and 38 “daily activities” and “physical functioning” were the most impacted areas of life in France.





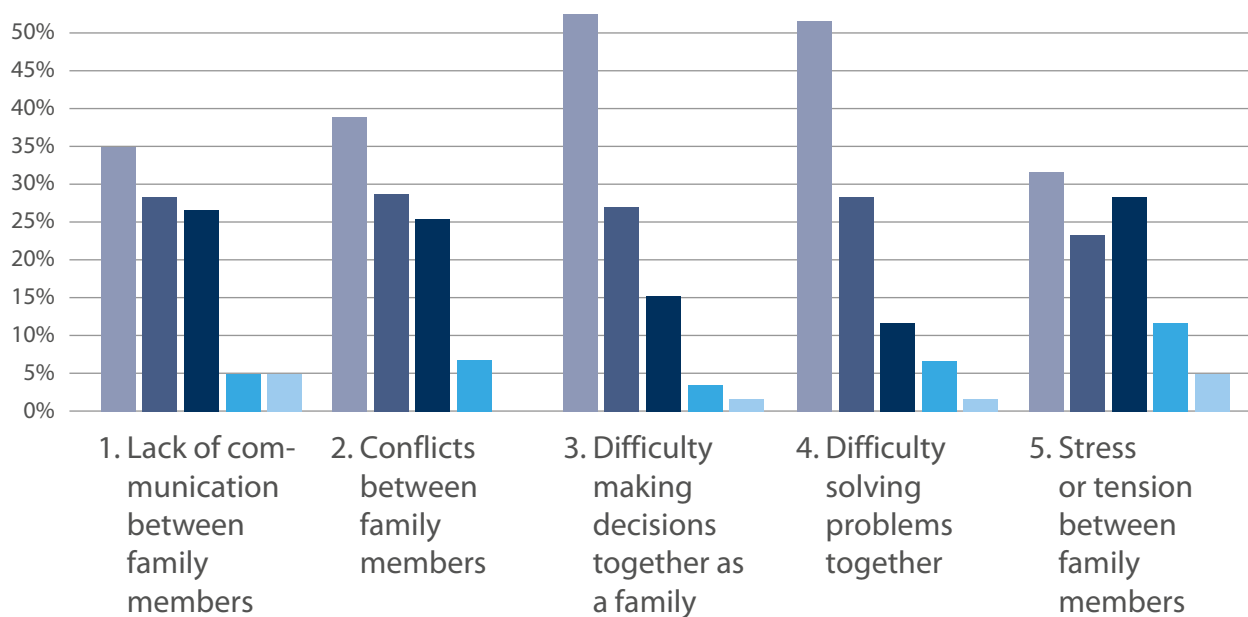
Daily activities

Never Almost never Sometimes Often Almost always



Family relationships

Never Almost never Sometimes Often Almost always



HEALTH LITERACY AND DISEASE AWARENESS

15% have not been aware of the disease and its possible consequences for the child



10% have not been aware of measures for preventing RSV

Nearly half of all participants (45%)

were not aware of the consequences of the child's RSV infection and hospitalisation for the entire family

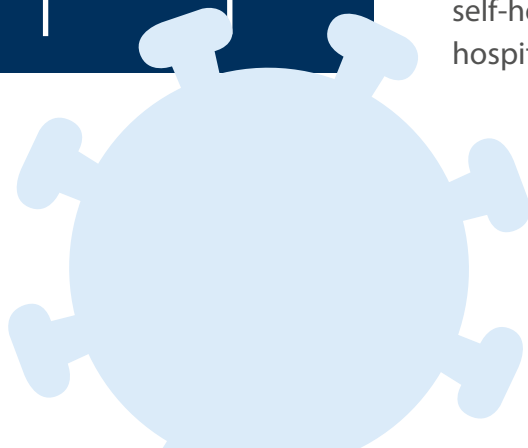
COMMUNICATION, HEALTH INFORMATION AND (MENTAL) HEALTH SUPPORT

17% have received no or no adequate information about how to protect the child from reinfection with RSV after hospital discharge.



Over 2/3 of all participants (69%)

did not receive any information or did not feel adequately informed about mental health support, e.g. in the form of counselling, self-help or parent groups, during the child's hospitalisation due to RSV.



GERMANY



About one third
of the participants

34%

felt often or always **guilty** for
not having prevented the RSV
infection of their child



59%

felt often or always
stressed about their
child's health status

81%

stated that they experienced
the feeling of **loneliness**
always, often or at least
sometimes



FEELINGS IN RELATION TO THE
CHILD'S HEALTH STATUS DURING
HOSPITALISATION

25% One in four participants
experienced **constant guilt** about
being separated from other family
members, such as other children or
their partner



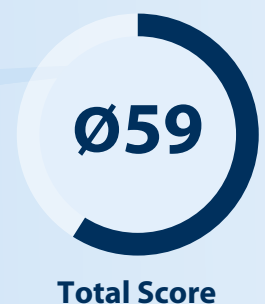
PARENTAL HEALTH-RELATED QUALITY OF LIFE AND FAMILY FUNCTIONING



All scores are ranging from 0-100, with higher scores standing for better functioning in each dimension and summary scores and thus less perceived impact of the RSV infection on the parents' HRQoL or family functioning.



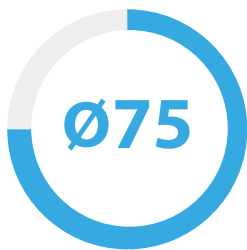
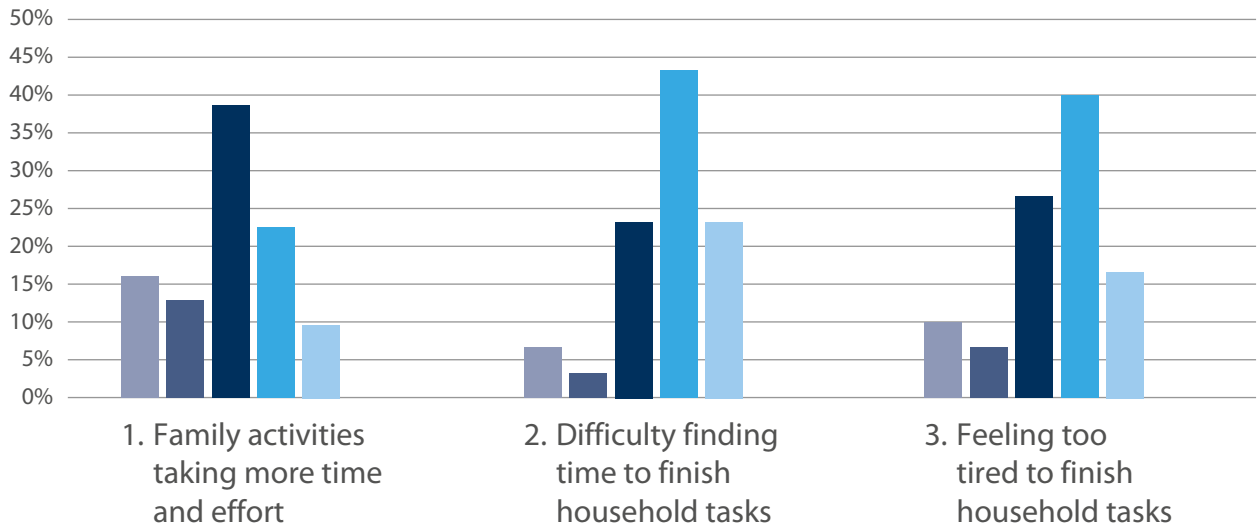
With an average of 33 “daily activities” was the most impacted area of life in Germany.





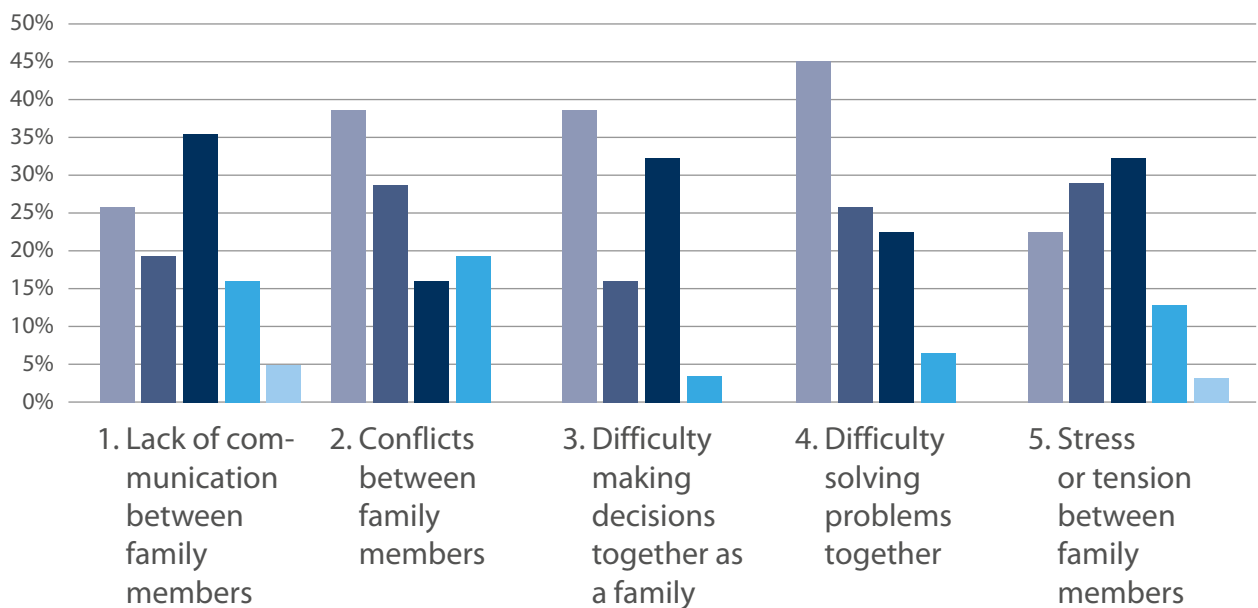
Daily activities

Never Almost never Sometimes Often Almost always



Family relationships

Never Almost never Sometimes Often Almost always



HEALTH LITERACY AND DISEASE AWARENESS

41% have not been aware of the disease and its possible consequences for the child



56% have not been aware of measures for preventing RSV

More than half of all participants (53%)

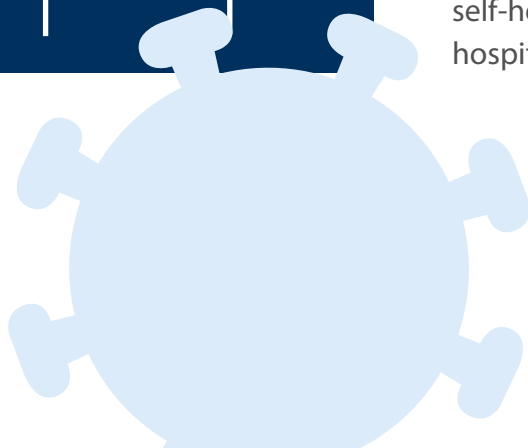
were not aware of the consequences of the child's RSV infection and hospitalisation for the entire family

COMMUNICATION, HEALTH INFORMATION AND (MENTAL) HEALTH SUPPORT

74% have received no or no adequate information about how to protect the child from reinfection with RSV after hospital discharge.



Nearly 3/4 of all participants (74%) did not receive any information or did not feel adequately informed about mental health support, e.g. in the form of counselling, self-help or parent groups, during the child's hospitalisation due to RSV.



ITALY



Nearly one third
of the participants

32%

felt often or always **guilty** for
not having prevented the RSV
infection of their child

FEELINGS IN RELATION TO THE CHILD'S HEALTH STATUS DURING HOSPITALISATION

61%

felt often or always
stressed about their
child's health status

„I'm very angry. I was informed about
the syncytial virus and I had intuition that
this could be it. I dragged my oldest, 3 years old
and the first to get sick, several times to paedia-
trician [...]. I changed hospitals the third time he
was finally taken care of now with pneumonia. The
day after, the second 11-month-old boy was also
hospitalised with RSV pneumonia. First aid [...]
worthless, disrespectful, superficial staff [...]“

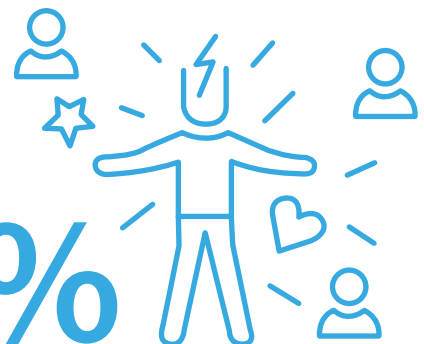
*Italian mother of a term born child
hospitalised with 350 days
of age*

82%

stated that they experienced
the feeling of **loneliness**
always, often or at least
sometimes

43%

experienced constant guilt about
being separated from other family
members, such as other children
or their partner



PARENTAL HEALTH-RELATED QUALITY OF LIFE AND FAMILY FUNCTIONING



All scores are ranging from 0-100, with higher scores standing for better functioning in each dimension and summary scores and thus less perceived impact of the RSV infection on the parents' HRQoL or family functioning.

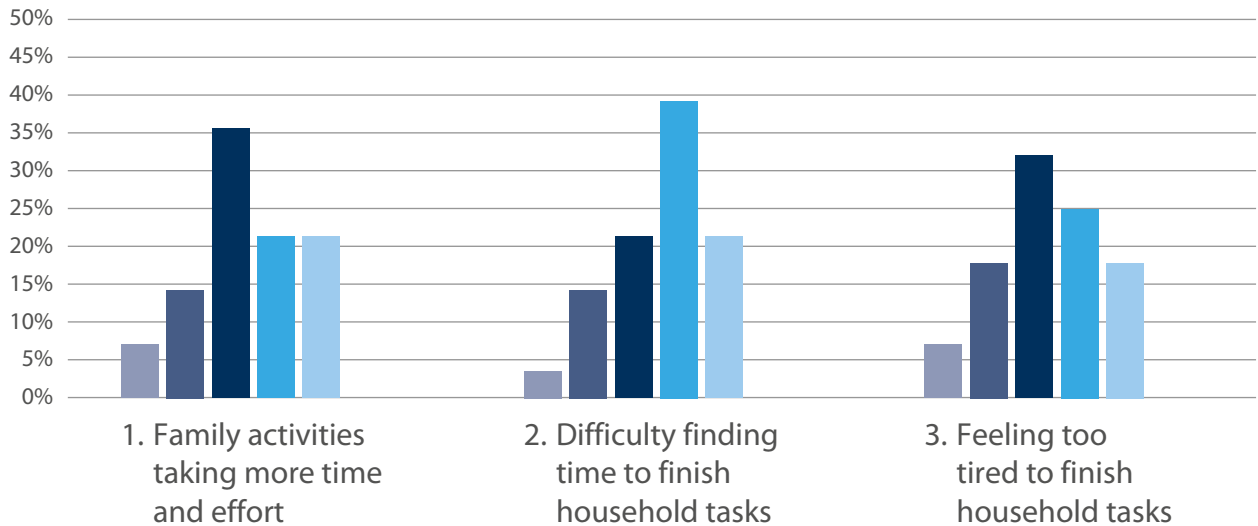


With an average of 33 “daily activities” was the most impacted area of life in Italy.



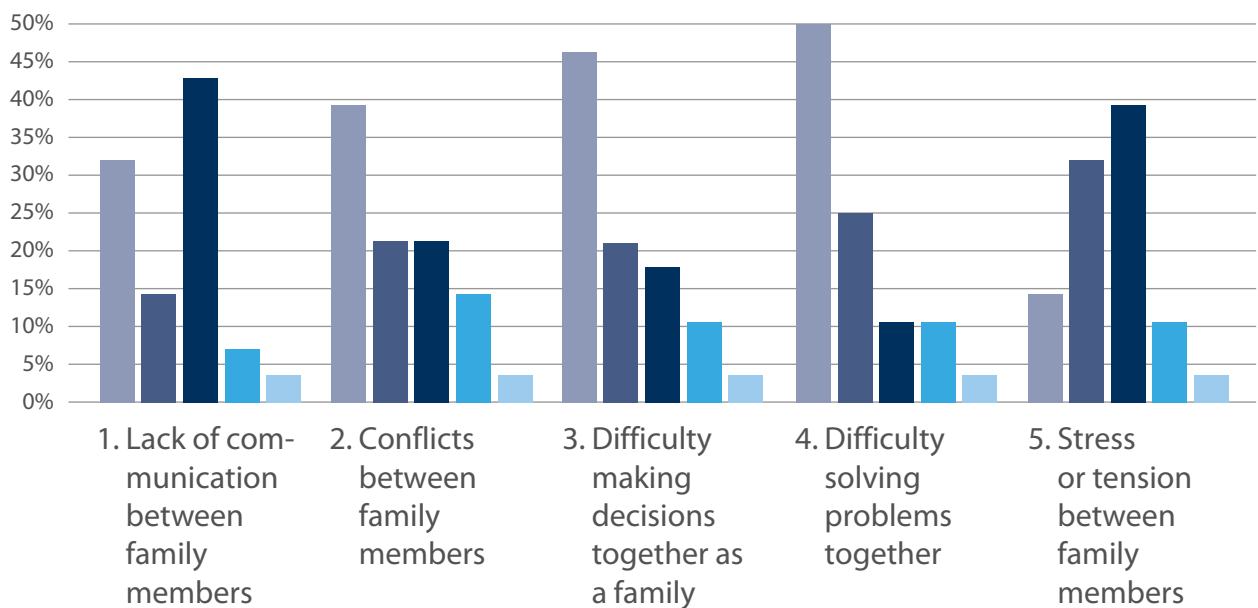
Daily activities

Never Almost never Sometimes Often Almost always



Family relationships

Never Almost never Sometimes Often Almost always



HEALTH LITERACY AND DISEASE AWARENESS

25% have not been aware of the disease and its possible consequences for the child



50% have not been aware of measures for preventing RSV

More than half of all participants (54%)

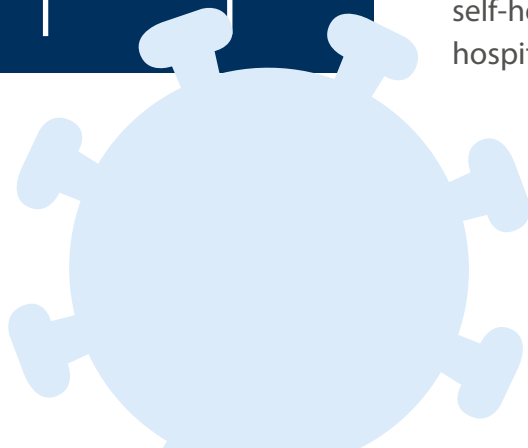
were not aware of the consequences of the child's RSV infection and hospitalisation for the entire family

COMMUNICATION, HEALTH INFORMATION AND (MENTAL) HEALTH SUPPORT

46% have received no or no adequate information about how to protect the child from reinfection with RSV after hospital discharge.



Over 3/4 of all participants (79%) did not receive any information or did not feel adequately informed about mental health support, e.g. in the form of counselling, self-help or parent groups, during the child's hospitalisation due to RSV.



SWEDEN

“

„Probably our little one was infected with RSV from her big brother who lives at home every other week. We have tried as best we can to keep him away from her the times he has been sick but it is difficult under the same roof. As a mum, I have often felt frustrated at not being able to protect her 100%, while at the same time feeling guilty towards her big brother, it's not his fault and he does the best he can [...]”

Swedish mother of a moderate to late preterm born infant hospitalised with 44 days of age

40%

felt often or always **guilty** for not having prevented the RSV infection of their child

FEELINGS IN RELATION TO THE CHILD'S HEALTH STATUS DURING HOSPITALISATION

63%

felt often or always **stressed** about their child's health status

83%

stated that they experienced the feeling of **loneliness** always, often or at least sometimes

33%

1/3 of the participants experienced **constant guilt** about being **separated** from other family members, such as other children or their partner



PARENTAL HEALTH-RELATED QUALITY OF LIFE AND FAMILY FUNCTIONING



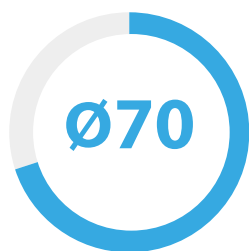
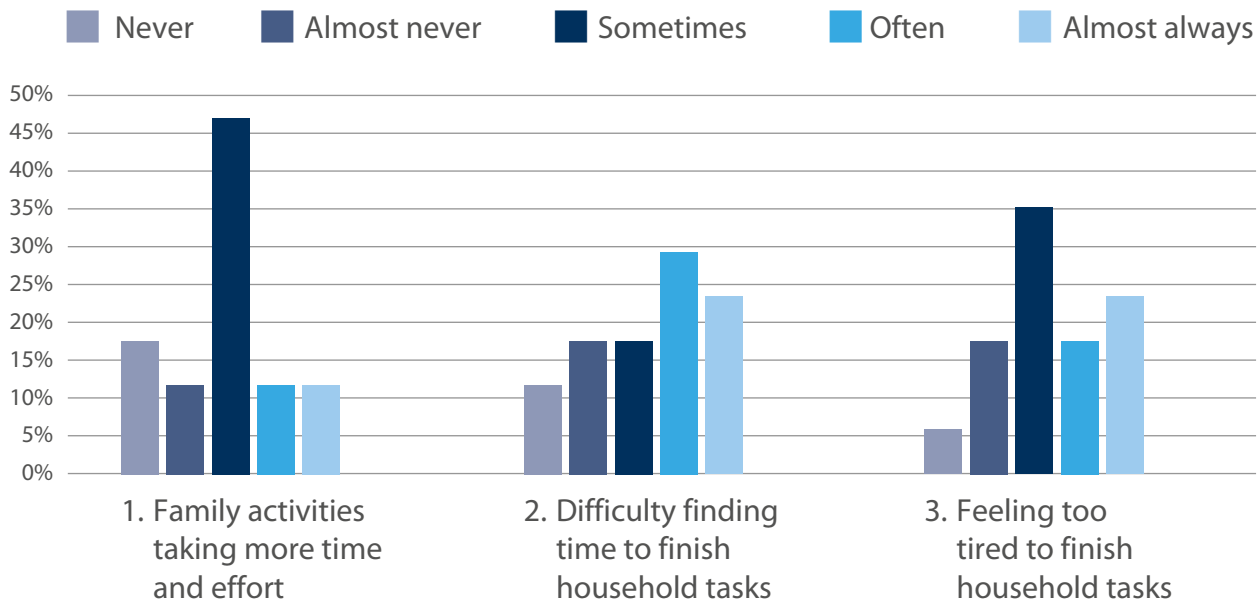
All scores are ranging from 0-100, with higher scores standing for better functioning in each dimension and summary scores and thus less perceived impact of the RSV infection on the parents' HRQoL or family functioning.



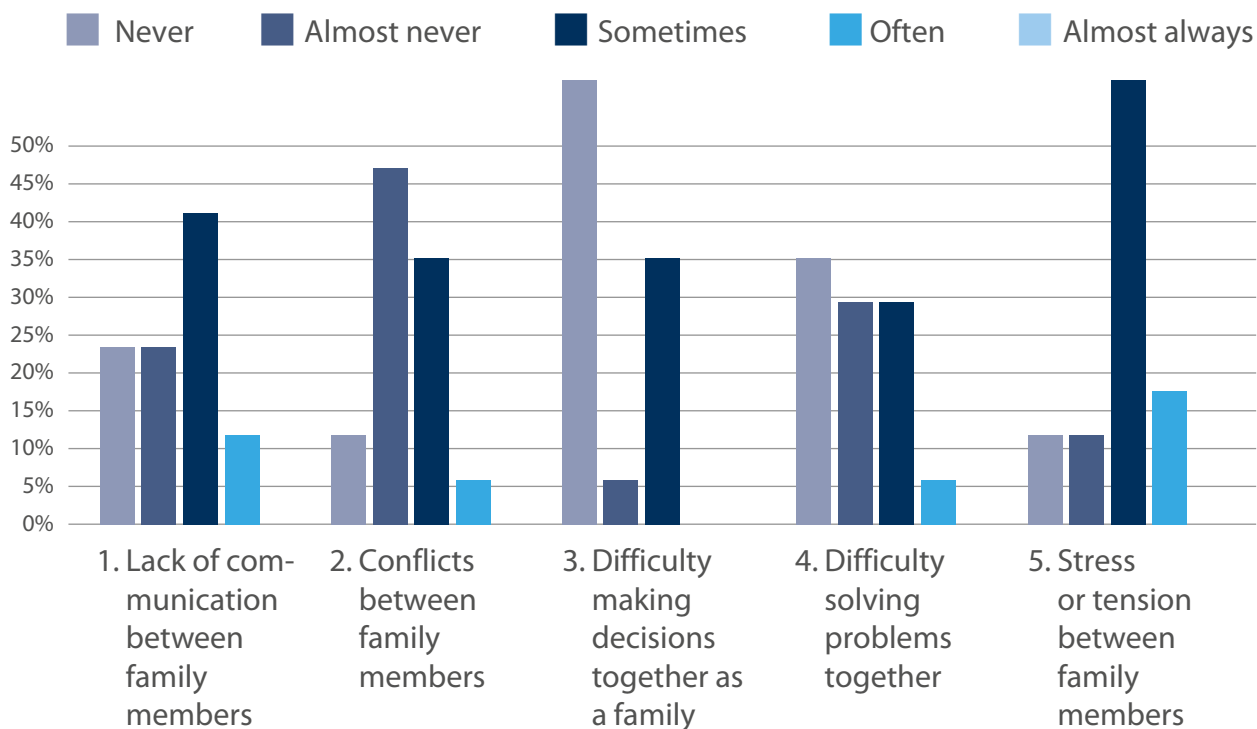
With an average of 42 and 44 “daily activities” and “social functioning” were the most impacted areas of life in Sweden.



Daily activities



Family relationships



HEALTH LITERACY AND DISEASE AWARENESS

6% have not been aware of the disease and its possible consequences for the child



6% have not been aware of measures for preventing RSV

Nearly half of all participants (44%)

were not aware of the consequences of the child's RSV infection and hospitalisation for the entire family

COMMUNICATION, HEALTH INFORMATION AND (MENTAL) HEALTH SUPPORT

Over half of all participants (53%) have received no or no adequate information about how to protect the child from reinfection with RSV after hospital discharge.



61% did not receive any information or did not feel adequately informed about mental health support, e.g. in the form of counselling, self-help or parent groups, during the child's hospitalisation due to RSV.



CONCLUSION

Severe RSV infections accompanied by hospitalisation are not only painful and exhausting experiences for the infant itself, they also represent a considerable burden for the entire family.

Our results show that in particular in the acute phase of the RSV infection, the health-related quality of life, mental wellbeing and daily family life are severely impaired across all four participating countries. Caring for sick children affects parents in many ways – stress and burden levels are at an all-time high. They have to take on additional, sometimes anxiety-inducing tasks such as health monitoring and intensive caregiving apart from balancing daily tasks associated with other family members, professional and social lives. It is therefore important to primarily prevent a severe infection from the outset by raising awareness for the disease and advancing prevention measures such as passive immunisation/vaccination for infants or mothers, which are currently being implemented in many countries. When an infection occurs, potential stressors but also beneficial factors associated with this challenging period, need to be emphasised in order to minimise the negative impact of the disease on the quality of life of the entire family. **The voice of parents and caregivers must be heard** by offering support structures such as mental health support and encouraging good and respectful family relationships during the acute infection phase along with the infant's hospital stay.

KEY MESSAGES



Ensure passive immunisation/vaccination for all children under two years of age as soon as possible to prevent severe RSV infections from the outset.



Value, include and empower parents as key caregivers of their children at all times.

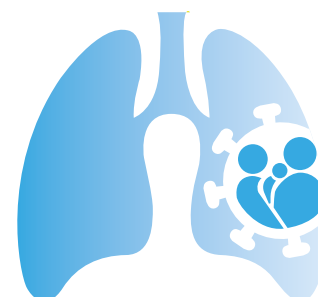


Offer and provide access to mental health support to parents and families during the acute infection phase in hospital.



Ensure adequate provision of health information and continuous as well as respectful communication between healthcare professionals and parents including after discharge.

THANK YOU



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IMPRINT



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About EFCNI

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

For more information: www.efcni.org



ResQFamily