

REGULAR ARTICLE

Interaction between healthcare professionals and parents is a key determinant of parental distress during childhood hospitalisation for respiratory syncytial virus infection (European RSV Outcomes Study [EROS])

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Keywords

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ABSTRACT

Aim: We characterised the distress that parents experienced when their child was hospitalised for respiratory syncytial virus (RSV) infection.

Methods: This survey-based, observational study was conducted during 2014–2015. Meetings were held in Spain and Italy, with 24 parents of RSV hospitalised infants and 11 healthcare professionals experienced in RSV, which identified 110 factors related to parental distress. The resulting questionnaire was completed by another 105 Spanish and Italian parents and 56 healthcare professionals, to assess the impact these factors had on parental distress, using a scale from 0 to 10 (very unimportant to very important).

Results: The five most important factors for parents were: healthcare professionals' awareness of the latest developments, readmission, reinfections, painful procedures and positive experiences with healthcare professionals. Healthcare professionals associated only medical factors with a meaningful impact on parents. Half of the six medical factors were given similar importance by both groups and the overall scoring for the 110 factors was comparable, with a correlation coefficient of 0.80. A primary concern on discharge was ongoing support.

Conclusion: The relationship between parents and healthcare professionals was a significant factor in determining parental distress. Healthcare professionals appeared to have a good understanding of the overall impact on parents, particularly the key medical factors.

INTRODUCTION

Respiratory syncytial virus (RSV) is a major cause of lower respiratory tract infections (LRTIs) and is the leading cause of childhood hospitalisation worldwide (1,2). The vast majority of hospitalisations for RSV occur in the first year of life (2–4), mostly in previously healthy infants born full term (3,5). Infants born prematurely and children with underlying medical conditions, such as congenital heart disease and chronic lung disease, are known to be particularly vulnerable to severe RSV infection (5–8).

Whereas the healthcare implications of severe RSV infection are well documented in terms of acute hospitalisation (2,4,7,9) and longer-term respiratory morbidity

(10–12), few studies have investigated the impact on parents of having a child hospitalised with an RSV LRTI. A

Key notes

- With the participation of a study population of 105 parents and 56 healthcare professionals we investigated the parental distress experienced when children were hospitalised with respiratory syncytial virus infection.
- The key factors for parents were: healthcare professionals' awareness of the latest developments, readmission, reinfections, painful procedures and positive experiences with healthcare professionals.
- Whereas healthcare professionals appeared to have a good overall understanding of parental distress, the importance of having a positive relationship with the parents was a key finding.

Abbreviations

LRTI, Lower Respiratory tract infection; RSV, Respiratory syncytial virus.

prospective study of 46 RSV hospitalised infants under 30 months of age and born at up to 35 weeks of gestation and 45 age-matched control subjects quantified the magnitude of child, caregiver and family distress associated with the hospitalisation and the 60-day post-hospitalisation recovery period (13). The study reported that the more severe the child's RSV infection and the poorer their health and functional status, the greater the caregiver's level of distress during the hospitalisation phase of the illness. Furthermore, the impact of hospitalisation on parents and siblings continued after the child's discharge from hospital (13). Similar findings were reported in an observational study that used the Bronchiolitis Hospitalization Questionnaire to assess the impact on parents of their child being hospitalised for bronchiolitis (14,15). The parents of 463 infants who were hospitalised for bronchiolitis, including 72% born full term, completed the questionnaire. The impact was found to be multifaceted, related to emotional, physical and organisational factors and persisted for up to three months after hospital discharge (14). Other research has shown that the caregivers of children hospitalised for RSV LRTI face a significant financial burden (16).

The primary objective of the European RSV Outcomes Study (EROS), conducted in Spain and Italy, was to characterise the key factors relating to the distress that parents experienced when their child was hospitalised with an RSV LRTI. The secondary objectives included the determination of how accurately healthcare professionals involved in the management of these children perceived and empathised with parental distress, how the impact on the parents compared during their child's hospitalisation and after discharge and whether parental distress was similar in Spain and Italy.

PATIENTS AND METHODS

Study design

This survey-based, observational, non-interventional study was conducted in two parts over 2014–2015. The aim of part one was to identify all the key factors and issues potentially relating to the parental impact of having a child hospitalised with an RSV LRTI. This was accomplished by holding five meetings each involving at least four unrelated parents of children previously hospitalised for RSV infection and two healthcare professionals, namely physicians and nurses, experienced in RSV. Meetings were held in Spanish hospitals in Madrid and Bilbao and Italian hospitals in Turin and Verona. Two meetings were held in Madrid and one in each of the other locations. The parents, who could be the mother or father, had to be at least 18 years of age and have had a child hospitalised with confirmed RSV LRTI in the last two years when aged less than 24 months. Parents were selected by working chronologically backwards from the most recent discharges for RSV hospitalisation. At each meeting, six questions about the experience of having a child hospitalised for RSV were presented in turn to the parents and healthcare professionals, with each participant asked to write down all the factors

that came to mind, regardless of how unusual or trivial they seemed. Participants were initially given five minutes to complete each question (Appendix S1) and, at the end, they took turns to read out their responses to stimulate further thoughts from the other participants. All of which were documented. The results from each of the meetings were collated and used to construct a structured questionnaire, which constituted the second part of the study.

The remit of the questionnaire was to assess objectively the importance and contribution of each of the factors identified. It was not intended to provide a direct measure of the level of overall distress since there was no comparator group of parents whose children had not had an RSV LRTI in the first two years of life. Within the questionnaire, each factor was scored on an end-anchored analogue scale from zero for very unimportant to 10 for very important, in the context of two scenarios: during hospitalisation and immediately following discharge. The order of the individual factors was randomised for scoring within each scenario.

Parental and healthcare professional versions of the questionnaire were developed, which were identical except for the phraseology used and the background information collected. For parents, the latter included whether the mother or father had taken part, the child's sex, their gestational age at birth, the presence of certain medical conditions diagnosed prior to their RSV hospitalisation – namely chronic lung disease, congenital heart disease, wheezing or eczema – the child's age at RSV admission, any admission to a neonatal intensive care unit or paediatric intensive care unit, the need for supplementary oxygen and, or, ventilation use, the overall length of stay in hospital and parents' working history at the time of the RSV hospitalisation. For the healthcare professionals, this included whether they were a physician or nurse, the number of years they had worked in paediatrics and an estimate of how many RSV cases in which they had been personally involved. The questionnaires can be viewed here: www.strategen-dev.co.uk/eros.

The questionnaire was completed by parents and healthcare professionals in Spain and Italy who had not taken part in the previous meetings. The target was to collect 50 parent questionnaires and 25 healthcare professional questionnaires that had been completed in each country. From our experience, 25 completed questionnaires typically yield statistical significance for differences of two analogue scale points. The same inclusion criteria were used for the questionnaire respondents as for the meeting participants and the parents were identified in the same manner. The questionnaires, which took 20–30 minutes to complete, were fulfilled during meetings organised within hospital premises in order to ensure a 100% response rate amongst those who attended.

Analysis of questionnaire

Principal component analysis was used to define the components of the stress environment in which the parents might have found themselves during the course of the

disease, as the infant progressed from initial admission to discharge. Any differences experienced or perceived between the period of hospitalisation and those on and after discharge were explored by linear discriminant function analysis. For both analyses, missing data were handled using the default, system mean. The data from an intercept on an end-anchored analogue line are, by definition, parametric, as the values are continuous and on a linear scale. Hence, *t*-tests were used to compare individual and aggregate scores for factors across the scenarios and the two groups, namely parents and healthcare professionals. The *t*-tests were used to provide further insights into the relative impact and importance of the factors and any differences in emphasis of the individual factors or combinations of factors between the scenarios and groups. The chi-square test was used to compare the baseline characteristics between the groups. The intensity of any association in the pattern of responses between the scenarios and groups was assessed by Pearson correlation. All analyses were carried out using SPSS for Windows 15.0 (IBM Corporation, New York, USA) and Excel 2010 (Microsoft Corporation, Washington, USA).

RESULTS

Initial meetings

The initial meetings were attended by 24 unrelated parents of RSV hospitalised children: 14 were Spanish and 10 were Italian. Of the 11 healthcare professionals – eight doctors and three nurses – who were also involved, seven were Spanish and four were Italian. A total of 110 factors (Appendix S2) were identified that potentially related to the parental impact of RSV hospitalisation: 46% were medically related and covered areas such as treatment concerns; 24% were family or socially related, such as disruption to family life; 16% were financial factors that included travel to and

from the hospital and 15% were personal factors, such as anxiety and stress.

Questionnaire

A total of 161 questionnaires were completed: 105 by parents – 59 Spanish and 46 Italian – and 56 by healthcare professionals – 31 Spanish and 25 Italian. The parents were mostly mothers (78%), around half (51%) of the children had been no more than three months of age at the time of their RSV hospitalisation, 71% had spent 4–14 days in hospital, and 29% had been admitted to intensive care (Table S1). Wheezing, defined as at least three episodes over a year, or asthma was reported in 44% of the children. The healthcare professionals were mostly doctors (58%), complemented by nurses (40%) and others (2%). Of these, 60% had more than 10 years' experience in paediatrics and 71% had been involved with more than 50 cases of RSV LRTIs (Table S2).

Key factors associated with parental impact

Of the 110 factors, the one which was identified as the most important for the parents across both the hospitalisation and discharge scenarios was the need to be sure that clinical staff were aware of latest developments and improvements (Table 1). The mean scores for the top five factors were 7.7–8.2 of 10, and two of the top five most important factors related to the parents' interactions with healthcare professionals. Other important factors were associated with medical issues. The mean score for all 110 factors was 5.6 and did not vary whether the children required intensive care or not (5.5 versus 5.9, respectively, $p = 0.176$).

The most important financial factor was having to rearrange work schedules or take time off, with a ranking of 59/110 (mean score 5.77). This was despite the fact that 34% of the parents reported having to take time off work as a result of the RSV hospitalisation: 40% for less than one

Table 1 Key factors/issues associated with parental burden

Factor/Issue	Ranking parents*	Ranking HCPs*	Parents' mean score† (SD)	HCPs' mean score† (SD)	p-value‡
Need to be sure that clinical staff are aware of latest developments and improvements	1	–	8.2 (7.0)	6.6 (2.3)	0.003
Worry that your child will have to be readmitted at a later date	2	4	8.1 (2.0)	7.8 (1.8)	NS
Becoming fearful of further infections	3	3	8.0 (2.3)	7.9 (1.8)	NS
Stressful, painful or invasive procedures during treatment	4	6	8.0 (2.3)	7.6 (2.1)	NS
Positive experience of treatment by healthcare professionals	5	–	7.7 (2.2)	7.0 (2.0)	0.010
Serious breathing difficulties and/or need for respiratory therapies	–	1	7.4 (2.6)	8.0 (1.5)	0.017
Problems normally associated with prematurity being further exacerbated	–	2	7.4 (2.7)	7.9 (1.3)	0.025
Ongoing health issues for your child, such as otitis, asthma, pneumonia, persistent cough	–	5	7.1 (3.0)	7.7 (1.7)	0.021
All 110 factors/issues combined	–	–	5.6 (1.0)	6.0 (1.0)	0.037

HCPs = healthcare professionals; NS = not significant; SD = standard deviation.

*Principal component analysis.

†Scored from 1 (very unimportant) to 10 (very important).

‡*t*-test.

week, 53% for one to two weeks and 7% for more than two weeks. RSV hospitalisation was also associated with a detrimental impact on work productivity, with 19% reporting a severe impact, 18% reporting the impact was moderate, and 63% reporting it was mild.

Parental and healthcare professional perspectives

The overall pattern of responses to all factors across both scenarios for parents and healthcare professionals was significantly correlated (0.80, $p < 0.001$). Of the five most important factors to parents, two were similarly rated by healthcare professionals with another ranked 6/110; all were related to medical issues (Table 1). Whereas parents reported that their interactions with healthcare professionals had had a significant impact on the distress they felt (score 7.7–8.2), healthcare professionals associated only medically –related factors with a meaningful impact on parents. Healthcare professionals tended to overestimate the importance of financial factors on parents and their mean score across 17 financially –related factors was 5.3 compared to 4.2 for the parents ($p < 0.001$). When it came to the combined score for the importance of all 110 factors to the parents, the healthcare professionals awarded this a higher mean score than the parents themselves (6.0 versus 5.6, $p = 0.037$). Of the 110 factors, 46 were scored differently by the parents and healthcare professionals: 10 were scored higher by the parents and 36 were scored higher by healthcare professionals (Table S3).

During RSV hospitalisation versus following discharge

The parents expressed similar concerns following their child's discharge from hospital, compared to when they were hospitalised, but they scored the importance of the 110 factors slightly lower (5.5 versus 5.7, respectively, $p < 0.001$). Only two individual scores changed significantly, both being lower following discharge than during hospitalisation. These were providing comfort and support for their child in hospital (6.5 versus 7.6, respectively, $p = 0.015$) and serious breathing difficulties and, or, the need for respiratory therapies (7.0 versus 7.8, $p = 0.043$).

In the multivariate analysis, two factors were found to be significant drivers of parental distress between the two scenarios. Providing comfort and support for their child in hospital was associated with hospitalisation, while the need for clinicians to have better training was associated with discharge. Other factors positively associated with hospitalisation (all $p < 0.01$) related to having good contact with healthcare staff, feeling they received positive treatment from healthcare staff and having a positive experience of the paediatric intensive care unit.

Spain versus Italy

The parents who responded in Spain and Italy were similar in that the majority were mothers (78% versus 80%, respectively) who had had infants hospitalised for RSV LRTIs at up to six months of age (70% versus 70%; Table S1). However, the children of the Spanish parents were more likely to have been born prematurely at less than

36 weeks of gestational age than the Italian children (70% versus 36%, respectively). They also reported a more severe course of disease than the Italian children, as indicated by an overall hospital length of stay of at least one week (55% versus 32%) and intensive care admission (41% versus 11%). A higher proportion of doctors completed the questionnaires in Spain than Italy (81% versus 27%, respectively) and the Spanish healthcare professionals also had more experience in managing RSV LRTIs: 93% had managed more than 50 cases compared with 41% of their Italian counterparts (Table S2).

The overall pattern of responses was significantly correlated between the Spanish and Italian parents and healthcare professionals, with correlation coefficients of 0.68–0.83 ($p < 0.001$ for all comparisons). A key factor that was identified by all groups of respondents was the concern that the child would need to be readmitted at a later date (Table 2). Of the five most important factors, two were shared between the Spanish and Italian parents. Spanish parents tended to score the importance of all factors higher than the Italian parents with a mean for the 110 factors of 6.1 versus 5.0, respectively ($p < 0.001$). Spanish and Italian healthcare professionals were very much in agreement, with four of the top five factors being the same and the mean scores for all 110 factors being similar (5.8 versus 6.2, respectively $p = 0.177$). Spanish healthcare professionals recognised two of the top five factors reported by Spanish parents, while Italian healthcare professionals recognised three of the top five for their parents, including the top two factors. However, there was greater agreement between the Spanish healthcare professionals and parents when it came to their overall scoring of the factors: for the Spanish healthcare professionals and parents, 5.8 versus 6.1 ($p = 0.282$), respectively, and for the Italian respondents, it was 6.2 versus 5.0 ($p < 0.001$).

DISCUSSION

The EROS study provides valuable insights into the distress felt by Spanish and Italian parents when their child was hospitalised with an RSV LRTI. A key finding was that a considerable proportion of the impact on the parents was related to their interactions and confidence in the healthcare professionals caring for their child. Of the five most important factors, two were associated with these healthcare professional interactions and relationships, including the highest ranked factor that staff needed to be aware of the latest developments and improvements. While the overall distress felt by the parents diminished after discharge, a significant concern that remained was the ongoing healthcare professional support they would receive. The key message from this is that maintaining confidence in medical staff and facilities is a pre-eminent factor in reducing parents' perceived distress. Allied to this is the fact that parents expect, and want, healthcare professionals to undergo continuing education on RSV and, therefore, it is important that such programmes are designed and implemented.

Table 2 Key factors/issues associated with parental burden split by country

Factor/Issue	Ranking Spanish parents*	Ranking Italian parents*	Ranking Spanish HCPs*	Ranking Italian HCPs*
Need to be sure that clinical staff are aware of latest developments and improvements	1	–	–	–
Worry that your child will have to be readmitted at a later date	2	2	3	2
Stressful, painful or invasive procedures during treatment	3	–	4	–
Becoming fearful of further infections	4	1	–	1
Having to maintain confidence in healthcare staff	5	–	–	–
Positive experience of treatment by healthcare professionals	–	3	–	–
Serious breathing difficulties and/or need for respiratory therapies	–	4	1	5
Need for parents to be involved in nasal washes or other treatments	–	5	–	–
Problems normally associated with prematurity being further exacerbated	–	–	2	3
Ongoing health issues for your child, such as otitis, asthma, pneumonia, persistent cough	–	–	5	4

HCPs = healthcare professionals.

*Principal component analysis.

Other key factors associated with parental distress were related to medical issues, in particular the fear of reinfection necessitating readmission. It was comforting to see that healthcare professionals seemed, in general, to empathise well with the distress felt by parents, particularly in relation to the medical factors. However, there were some potential key lessons and educational messages for healthcare professionals that arose from the study result. Firstly, they needed to keep parents well informed and not assume that medical issues were too complicated for them to appreciate. Secondly, they needed to be aware that worry about post-discharge care was a significant issue for parents and must be managed. Finally, parents appeared to be good at managing the practical issues associated with their child's illness, and emotional and support issues for the infant were paramount. Other studies of RSV hospitalised children have reported that the parents' educational level, disease severity, hospital length of stay, watching the child undergo procedures and changes in parental roles, such as concerns about their not taking care of their child, were key drivers in determining parental distress (13–15). Hence, these factors should be taken into account when dealing with parents.

Our observations regarding the importance of the relationship between parents and healthcare professionals were consistent with other studies' examining the parental stress of having a child hospitalised (17–20). Miscommunication, such as conflicting or delayed information, between parents and healthcare professionals has been shown to worsen the hospital experience (17), while better parent–healthcare professional communication has been associated with lower parental stress (18). It is also been shown when parents deal with nurses they need to receive emotional support, they expect the nurses to be approachable and receptive to the parents' questions and anxieties, and they need them to project a friendly, rather than critical, attitude (20).

The financial impact on parents of having a child hospitalised for RSV LRTI has been shown to be substantial. In a 2003 US study (16), the average cost per admission was US\$4,517 for premature infants and US\$2,135 for term infants, which included out-of-pocket expenses and the value of the loss of productivity to society, based on the average hourly wage. However, these figures excluded inpatient hospital and physician bills and lost income (16). Managing RSV infections in the community has also

been associated with considerable indirect costs: an Australian study that used data from 2003 to 2004 reported a mean cost of AU\$304 per episode (21). In our study, financial factors were not shown to be a particularly important immediate issue for parents and the most salient of these factors, related to taking time off work, was ranked just 59 of 110 factors. Similar results were seen in a French study using the Bronchiolitis Hospitalization Questionnaire, where the financial impact on parents was the lowest of the 12 scores assessed (14). This was despite a considerable proportion of parents having to take time off work due to their child's RSV hospitalisation. In fact, 60% of our parents reported that they took at least one week off. In another study, 52% of the parents reported taking off at least 2.6 days (22). It is clear that the immediate overriding concern of the parents was the well-being of their child during hospitalisation rather than their finances.

There were a number of limitations to our study, particularly its retrospective nature. While we would expect that parents would remember a traumatic event that occurred within the last two years, we accept that some aspects of the perceived impact would have been tempered by time. In particular, some parents may have found it hard to separate their memories of the RSV hospitalisation period and the period immediately after discharge. Despite this, it is noteworthy that there were measurable differences identified between the two periods. These differences are likely to represent the most salient factors for parents, albeit that some of the more subtle aspects may have been lost. Other potential limitations include the fact that the respondents were a self-selected group and they may have suffered questionnaire fatigue as 7.8% of the scores were omitted. However, these are inherent issues with survey-based studies like ours. Despite the use of native Spanish and Italian speakers for translations, the risk of inadvertent translation inaccuracies was another potential limitation, though the similarity in the pattern of responses from the Spanish and Italian parents and healthcare professionals was reassuring in this regard and reinforced the reliability of the questionnaire. Arguably, the greatest strength of the study was that the factors used to characterise the impact on parents were all elicited and defined from first principles and they can be considered valid in terms of content and clarity, despite the absence of any formal testing. The fact that the order of the 110 factors was randomised in the questionnaire across two scenarios, admission and discharge, was also a key strength, as it would have been extremely difficult for any respondent, consciously or subconsciously, to convey a particular narrative through their responses, a risk that can be a source of potential problems when conducting research with the aid of questionnaires.

CONCLUSION

This study provides a greater understanding of the distress that parents experienced when they had a child hospitalised

with an RSV LRTI. This was a subject that had rarely been studied, despite the prevalence of RSV hospitalisation amongst children worldwide. Key factors related to parental distress included the parents' fears of further infections and readmission and, perhaps most importantly, their interactions and relationships with the healthcare professionals and confidence in their abilities to manage their child's illness. A greater understanding of the key drivers and concerns experienced by parents will hopefully lead to improved services and a better experience for parents at such a traumatic time in their and their infants' lives.

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CONFLICTS OF INTEREST

Xavier Carbonell-Estrany, Paolo Manzoni, Alberto Dall' Agnola, Elisa Girardi, Alessandro Mussa, Natalia Paniagua, Marta Pieretto and Rosa Rodríguez-Fernandez have acted as expert advisors and speakers for AbbVie and have received honoraria for this. Barry Rodgers-Gray, who wrote the first draft of the manuscript, and John Fullarton have worked on various projects for AbbVie for which their employer, Strategen, has received fees. The authors have no other conflict of interests to declare.

ETHICAL APPROVAL

The study did not require formal ethical approval in Italy. In Spain, the initial meetings did not require ethical approval, but the Agencia Española de Medicamentos y Productos Sanitarios was notified about the details of the actual

questionnaire as a nonpost-authorisation study. All the Spanish hospitals that were involved subsequently approved the questionnaire. All data were collected anonymously and participants could withdraw from the study at any time and for any reason.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Appendix S1 Different phraseology was used for HCPs.

Appendix S2 Catalogue item.

Table S1 Background information and characteristics of parents and RSV-hospitalised children.

Table S2 Background information on healthcare professionals completing questionnaire.

Table S3 Factors/issues that were scored significantly different by parents (n=105) and healthcare professionals (n=56) combined across both scenarios (during hospitalisation and following discharge).