

Caregivers' Perceptions and Hospital Experience After a Brief Resolved Unexplained Event: A Qualitative Study

Adrita Khan, MD,^a Sowdhamini S. Wallace, DO, MS,^a Esther M. Sampayo, MD, MPH,^b Carla Falco, MD^a

BACKGROUND AND OBJECTIVES: The American Academy of Pediatrics published guidelines for evaluation and management of lower-risk infants for a brief resolved unexplained event (BRUE). The guideline identified gaps in knowledge related to caregiver satisfaction, anxiety, and family-centered educational strategies to improve caregiver experience and patient outcomes. The objective of this study was to understand caregivers' experience with hospitalization for infants with BRUE, including their perception of the hospital stay, the diagnosis of BRUE, and their feelings toward the upcoming discharge from the hospital.

METHODS: We conducted a qualitative study using semistructured interviews with caregivers of infants aged 0 to 12 months who were admitted to a quaternary care children's hospital for a BRUE. Interviews were conducted within 24 hours of discharge. Two investigators coded transcripts and identified themes using consensus.

RESULTS: Eighteen caregivers of 13 infants were interviewed. No infants met criteria for being low risk according to the American Academy of Pediatrics guidelines. The coding scheme produced 3 major themes. First, parents felt reassured by hospital monitoring, diagnostic evaluation, and staff support in the hospital. Second, parents felt unsettled by the uncertainty of the child's condition and whether BRUE's "unexplainable" quality is understood as being part of normal infant behavior. Third, these themes manifested as conflicting emotions about caregivers' readiness for discharge.

CONCLUSIONS: Although hospital monitoring may provide reassurance for some caregivers, they continue to struggle with the uncertainty of the diagnosis. Caregiver perspectives can inform physicians' strategies to improve hospital experience and discharge readiness.

ABSTRACT

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Address correspondence to Adrita Khan, MD, Department of Pediatrics, Columbia University Medical Center, 622 W 168th St, VC-408C, New York, NY 10032. E-mail: aak2214@cumc.columbia.edu

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^aSections of Pediatric Hospital Medicine and
^bPediatric Emergency Medicine, Department of Pediatrics, Baylor College of Medicine, Houston, Texas

In 2016, the American Academy of Pediatrics (AAP) published a clinical practice guideline redefining the apparent life-threatening event as a brief resolved unexplained event (BRUE) and distinguishing between lower-risk and higher-risk infants. The AAP recommends limited testing and brief observation for lower-risk infants and suggests hospitalization for higher-risk infants without further specific recommendations.¹

For infants who are hospitalized, the hospital stay is a time for providers to deliver meaningful education to caregivers, address concerns, and prepare caregivers for discharge. Studies in which the experience of caregivers during hospitalization is broadly examined have revealed that parents' thoughts on discharge readiness are focused on the importance of education on their child's diagnosis and communication to build a partnership with providers.^{2,3} Caregivers often struggle to cope with uncertainty during their child's hospital stay, and the transition from the hospital to home involves assessing their own emotional discharge readiness.²⁻⁶ A lack of a shared perspective on a patient's condition between parents and providers has been associated with a lack of discharge readiness and increased risk of hospital readmission.⁷ The BRUE guidelines are used to encourage physicians to be resources for parents and echo the existing evidence that supports cardiopulmonary resuscitation (CPR) training for all caregivers and the general public, as recommended by the AAP.¹ However, knowledge gaps exist regarding caregiver satisfaction, anxiety, and understanding of infants with BRUE.¹

Therefore, further research focused on BRUE is needed to inform strategies to improve the hospital experience for caregivers. These infants and caregivers compose a population with potentially heightened anxiety among caregivers, limited evaluations, and short observation periods. Similar to sudden infant death syndrome, BRUE is unpredictable and without identified significant risk factors,^{8,9} which may contribute to parental anxiety. Qualitative research allows us to study the

knowledge and beliefs people have regarding a specific topic as it relates to their own experience and can help provide a detailed illustration of underlying constructs that affect caregivers during the hospitalization of their children. Our study objective was to describe caregivers' experience with hospitalization of infants with BRUE, including their perceptions of the hospital stay, of the diagnosis of BRUE, and of the upcoming discharge from the hospital.

METHODS

We conducted a qualitative study using semistructured interviews of caregivers of infants with BRUE who were hospitalized from February 2017 to June 2018 at a quaternary care children's hospital. Our institution uses an evidence-based clinical pathway for management of infants with BRUE who are hospitalized that mirrors the AAP guideline. The local institutional review board approved this study. All participants gave written informed consent before participation.

Demographic information on caregivers' age, race, education level, and occupation were collected during the interviews. Medical records of the patients were also reviewed, and data on the characterization of each BRUE episode were collected from the documentation in the admission note.

Study Population

We prospectively identified a convenience sample of caregivers of infants with an admission diagnosis of BRUE (*International Classification of Diseases, 10th Revision* code R13.68) using an electronic medical record data report. Eligibility was then determined by reviewing the infant's medical record. We included primary caregivers of infants aged 0 to 12 months who were admitted for clinical criteria consistent with a BRUE episode on admission, as described in the AAP clinical practice guideline for BRUE.¹

We excluded caregivers who were not available at the bedside. Non-English-speaking caregivers were also excluded because of the inability of investigators to interview caregivers with other spoken languages. We also excluded patients whose

symptoms were not resolved at the time of admission and therefore did not meet the BRUE definition.

Development of the Interview Guide

A semistructured interview question guide was developed after review of the literature and consultation with local and national content experts. The questions were then piloted with caregivers for feedback on content and comprehension. The interview guide was developed through an iterative process as data were collected and simultaneously analyzed, which is in step with qualitative research methodology.¹⁰ Specifically, we added more follow-up questions to let caregivers elaborate on their responses. The interview guide continued to reflect our study aims and was focused on caregivers' experience during hospitalization and feelings about discharge (Supplemental Information).

Data Collection

Caregivers were approached on their infant's anticipated day of discharge by the primary investigator (A.K.), who did not participate in the clinical care of these patients. A.K. conducted all interviews in a private room within 24 hours of discharge with guidance and oversight by research team members with qualitative expertise (C.F. and E.M.S.). Demographic information on age, race, education level, and occupation was also collected during interviews. All interviews were audio recorded and transcribed by the primary interviewer (A.K.). Data collection continued until thematic saturation was reached. Data on infant characteristics, the characterization of each BRUE episode, and the evaluations performed were abstracted from the medical record.

Data Analysis

Interview transcripts were analyzed concurrently with data collection. Codes were developed by using a constant comparison method; they were then grouped into categories to form themes. A conceptual framework was created to illustrate the perceived hospitalization experience described by our participants.

To address trustworthiness, C.F. co-led 2 interviews to offer guidance on the

interview technique. In addition, 2 members of the research team (A.K. and C.F.) individually reviewed the transcripts to identify codes and then met to arrive at a consensus through peer debriefing. The findings were reviewed with a third research member (E.M.S.) for further peer debriefing.

RESULTS

Eighteen caregivers of 13 infants with BRUE met eligibility criteria and were interviewed during 13 sessions. For 5 interviews, mother-father dyads participated in interviews together, and the remaining 8 interviews were conducted with the mother alone.

The caregivers were mostly women, were Hispanic, and had a high school degree (Table 1). The 13 infants had an average age of 3.0 months, and 10 infants were born term. Four infants had comorbidities aside from prematurity, which included chromosomal abnormalities,

gastroesophageal reflux, and genitourinary tract anomalies. The infants lived in households with an average of 2 children (range 1–6 children). None attended day care. Five infants were previously hospitalized, and of these, 3 required intensive care.

The presenting features of the BRUE had a varying combination of symptoms: 85% included a color change of cyanosis or pallor; 62% had absent, decreased, or irregular breathing; 54% were noted to have a marked change in tone; and 62% were reported to have had an altered level of responsiveness. All the infants in our study were categorized as having a higher-risk BRUE per the AAP clinical practice guideline definition.¹ The average length of stay for these infants was 1.3 days (SD 0.6). The evaluation and management performed during hospitalization of a large proportion of infants included electrocardiograms and pulse oximetry monitoring (Table 2).

Three major themes emerged regarding the experience of caregivers during the hospitalization of their infants: (1) reassurance during hospitalization, (2) uncertainty, and (3) conflicting emotions toward discharge. The interaction between these themes is illustrated by a conceptual framework in Fig 1. Representative quotes from caregivers that led to the identification of codes and themes are listed in Table 3.

Theme 1: Reassurance During Hospitalization

Inpatient monitoring, diagnostic evaluation, and staff support generally contributed to reassurance. Caregivers described feeling reassured during hospitalization because of the safety they experienced in the hospital (Table 3). Many caregivers' first impulse was to take their infant to a hospital "to get checked" or to "make sure" the infant was well. Continuous pulse oximetry monitoring was perceived as helpful because of the acute nature of BRUE to occur suddenly and unexpectedly, and monitoring facilitated the detection of new symptoms quickly. Having health care providers available to observe infants and be available should another event occur also led to a feeling of safety. In addition, caregivers reported feeling reassured by the negative workup to rule out other possible causes of their infant's episode. One caregiver said, "I just like to have tests ran even if there's nothing wrong just to make sure everything's still working good, heartbeat's good, no blood around his brain or anything." Even caregivers who noted their child's discomfort as a result of testing thought the testing to be worthwhile. Many caregivers noted that the combination of monitoring and negative test results made them feel comfortable that serious conditions were being ruled out, such as seizures or a cardiac abnormality. In recalling conversations with the medical team, the negative results reinforced that their child was a normal, healthy infant, although there was some ambivalence with the notion that such an alarming episode could be part of normal infant behavior. The overall reassurance and experience of safety in the hospital prompted a desire to go back to the caregiver's usual routine at home.

TABLE 1 Characteristics of Caregivers of Infants Hospitalized With BRUE

Characteristics of Caregivers (<i>N</i> = 18)	Value
Age, y, mean (SD)	28.9 (5.3)
Male sex, <i>n</i> (%)	5 (28)
Race, <i>n</i> (%)	
Hispanic	9 (50)
White	5 (28)
African American	2 (11)
Asian American	1 (28)
Unsure	1 (6)
Highest level of education, <i>n</i> (%)	
Graduate or professional licensing	0 (0)
Some college or undergraduate degree	10 (56)
High school diploma	7 (39)
Did not complete high school	1 (6)
Marital status, <i>n</i> (%)	
Married	5 (28)
Living together	11 (61)
Single	2 (11)
Occupation, <i>n</i> (%)	
Health care professional ^a	2 (11)
Work at home as primary caregiver	5 (28)
Other	8 (44)
Unemployed	2 (11)
Missing	1 (6)

^a Caregiver occupations in the health care field included 1 dental assistant and 1 nurse.

TABLE 2 Evaluation and Management Approach for 13 Infants Hospitalized With BRUE

Diagnostic Test or Treatment	Frequency (%)
Head imaging ^a	4 (31)
EEG	0 (0)
Electrocardiogram	9 (69)
Echocardiogram	0 (0)
Holter monitor	1 (8)
Chest radiograph	7 (54)
Laboratory tests ^b	8 (62)
Social work consultation	1 (8)
Medical subspecialty consultation ^c	3 (23)
Continuous pulse oximetry	9 (69)
CPR training	8 (62)

^a Head imaging included a head computed tomography scan ($n = 3$) and a head ultrasound ($n = 1$).

^b Eight infants received laboratory tests; laboratory tests included varying combinations of complete blood cell count, urine cultures, blood cultures, cerebrospinal fluid cultures, chemistry panels, respiratory viral panels, ammonia tests, venous blood gas analyses, and peripheral smears.

^c Medical subspecialty consultations included genetics ($n = 1$), infectious disease ($n = 1$), and neurology consultations ($n = 1$).

you know, just that we don't know a hundred percent is still a little concerning." Without a reason behind the event, they expressed concern over the possibility of a future event and were nervous about what to do if "something happens" again. Fear of the unknown led most caregivers to plan to be more alert to changes in their child (ie, they planned to "watch" their child more closely). Some parents tried to think of anything different about the infant's setting or routine that may have led to an event occurring. For some, being more vigilant meant checking on their infant more frequently during sleep; for others, this meant moving the infant's crib into the parent's bedroom. Caregivers noted that their worries may only be alleviated with time.

Theme 3: Conflicting Emotions Toward Discharge

Our conversations with caregivers often vacillated between reassurance and uncertainty, and these contradictory emotions emerged when we discussed the anticipated discharge from the hospital. Caregivers were consistently ambivalent about being ready for discharge. Often within the same sentence, they expressed both a desire and readiness to leave the hospital as well as a desire to stay longer because of anxiety about caring for the child at home without the medical support provided in the hospital setting and because of fear of a future event. Many were unsure of what would make them feel ready. One caregiver said, "Yeah, just uneasy. And like I said, it's nothing that the hospital or anybody could probably ease. It's just a mother's love." Others stated that having a concrete answer would offer more security. Despite these conflicting emotions, most caregivers were overall happy with how their medical teams communicated with them about the status of their child during rounds. Many felt more prepared for home with CPR training before discharge.

DISCUSSION

In this study, we describe the perspective of caregivers with infants admitted for higher-risk BRUE. Although we did not intend to restrict our population by risk status, all of

Theme 2: Uncertainty

Despite the reassurance caregivers gained with inpatient monitoring, they described feelings of uncertainty with their child's condition and with BRUE's "unexplainable" quality.

Although some caregivers viewed BRUE as the final diagnosis, others expressed that

the BRUE diagnosis was not clear enough or that another diagnosis was still possible. This lack of an answer left caregivers feeling frustrated and uncertain about what negative test results really meant.

One caregiver said, "I think the testing ruled things out. You know? So at least I don't have to be worried about those things. But

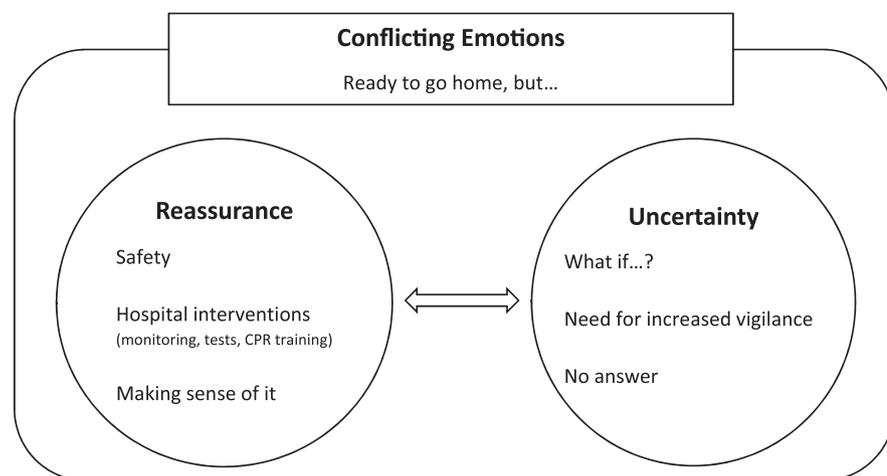


FIGURE 1 Conceptual framework of caregivers' perception of their hospital experience. Caregivers' conflicting emotions toward discharge arise from a waffling between 2 opposing feelings: feelings of reassurance that developed from the safety felt in the presence of medical providers in the hospital, from monitoring and testing, and from making sense of normal infant behavior and feelings of uncertainty that developed from a fear of a recurrence of the event, from a perceived need for increased vigilance at home, and from finding no answers for or cause of the unexplained diagnosis.

TABLE 3 Major Themes on Caregivers' Perceptions of Their Hospital Experience

Themes	Categories	Codes	Illustrative Quotes
Reassurance	Safety	<ul style="list-style-type: none"> • Safe in the hospital • Hospital stay made me feel better • Trust in the team • "Make sure" 	<p>"When you're here you're just like, 'What's going on?' But I feel safer here too because you know, it's a hospital. Everything here is medical and in case of an emergency, I'm already here."</p> <p>"I just knew that he would be in good hands and that was the main concern. So if anything happened, they knew how to react to his situation."</p>
	Hospital interventions	<ul style="list-style-type: none"> • Monitoring makes me comfortable • Reassurance with testing • Feel better with discharge instruction • Feel better with CPR training 	<p>"I think they put this issue to rest. I mean you know we checked out his heart, his heart is good. His head is good. Vital signs, good heartbeat. Doesn't [desaturate] when he's breathing less. So I mean I feel like, I don't know, I think we put this issue to rest pretty sufficiently."</p> <p>"It just makes me feel like they're really watching her, making sure she doesn't have another one while she's sleeping."</p> <p>"We already went through the CPR class once but he wants to show us the CPR class video again. It's always good to just refresh just in case, you never know with the little babies...so yeah, nice little steps for us to go home with, be more comfortable and relaxed with him."</p>
	Making sense of it	<ul style="list-style-type: none"> • How the team explained it • Normal behavior for infants • Infant looks better 	<p>"I understand. I mean I know infants just, they're not—they're new to this world. So I completely understand. I don't feel like they were sugar-coating anything or didn't want to look into it. It's understandable."</p> <p>"Yeah, unexplained event. It's basically unexplained, and I mean it blows my mind [laughs]. I don't know what to think. I'm like okay, I hope it's just that. Because it seems like they did a lot of—I mean, the scan, the testing already. Which is EKG, and then chest x-ray, and monitor for like 24 hours, and everything's benign, which is good."</p>
Uncertainty	What if...?	<ul style="list-style-type: none"> • Worry about an underlying problem • What if it happens again? • Fear of the future 	<p>"I'm okay. Just worried, you know, if it happens again. We'll be right back over here."</p> <p>"Just seeing him like that, it just looks really ugly. And I'm just afraid one day that he's gonna be in a deep sleep or I'm gonna check on him and I'm not gonna have woken him up soon enough."</p>
	Increased vigilance	<ul style="list-style-type: none"> • Watch him closely • Attentive • Alertness to changes 	<p>"Probably I would be more, more attentive, knowing that that happened one time, it could happen another time. So I will be more aware of everything."</p> <p>"I'll be more, what do you call it? Not overprotective, but more alert to check on her a whole bunch more."</p>
	No answer	<ul style="list-style-type: none"> • Unknown is concerning • No answer • Looking for cause, not finding it • Still worried with negative test results 	<p>"No, like I said, I'm still gonna walk out of here a little iffy and confused on what really was it. Because I did ask the doctor, two of the doctors last night, what exactly was the cause. He said they really can't point it out exactly what it is because he's so small. I understand that but at the same time, you guys ran all these tests. I would think that at least you know something. So I'm still gonna walk out of here, is it reflux or was it a seizure?"</p> <p>"So it's just something that he's—they assured us that it's normal for babies especially his age, which I can definitely see, but—it's still unknown. If it was something we could correct, with behavioral change or medicine, that would be great. But this is just something that we have to keep constant vigilance over."</p>
Conflicting emotions	Ready to go but...	<ul style="list-style-type: none"> • Relieved but not • Ready to go but worried 	<p>"I'm ready to go home but I feel safe here, because I have hands—I have the nurses, the doctors, they know what they doing. I feel more safe here, but at the same time I'm ready to go home. You know, he's tired of being here and poked 24/7 so, I don't know. I want to go home but, like I said I feel more safe. Y'all have more experience here, you know what I'm saying?"</p> <p>"I guess more reassuring. I mean I'm okay I guess that he doesn't have these other issues that they were worried about. But, I mean if it would have happened and more testing would have been done then I would have been okay, you know?"</p> <p>"Well, I feel relieved but not. Because like, there's a lot of unexplained medical things. But like, I mean I'm relieved because nothing's wrong with him at this time, but really not because if it happens again then more tests [are] needed."</p>

CPR, cardiopulmonary resuscitation; EKG, electrocardiogram.

our infants met classification criteria for higher-risk BRUE.¹ Using a qualitative approach, our analysis revealed feelings of reassurance and safety associated with the hospital stay versus being unsettled by the uncertainty or unexplainable quality of the BRUE diagnosis; discussion with parents revealed contradictory emotions among parents regarding their feelings toward staying in the hospital versus going home.

Factors of Reassurance

Gaining a deeper understanding of parents' perceptions needs during hospitalization can lead to decreased stress for caregivers.^{11,12} Our study illuminates the needs of caregivers of infants with higher-risk BRUE, revealing that monitoring, negative test results, observation, and support by hospital staff afforded the perception of safety. The knowledge of why caregivers value hospitalization in infants with higher-risk BRUE helps to frame the conversation with caregivers and can help shape future management recommendations. Although caregivers felt reassured by negative test results, they also described negative experiences associated with painful procedures, such as venipuncture. Providers can draw on these experiences of patient-centered risks, along with reassuring factors and test-associated risks (eg, false-positives¹⁵), to shape a family-centered conversation around further testing. Along the same lines, discussions with caregivers about the duration of monitoring in the hospital can balance the reassuring experience with the known risks of hospitalization and monitoring, such as nosocomial infections, false alarms with monitoring, or loss of wages by caregivers.¹⁴⁻¹⁸ Shared decision-making and an individualized approach to assessment of caregivers' needs and expectations may be even more important for caregivers of infants with higher-risk BRUE while we await evidence-based management recommendations for this population.

Handling Uncertainty

The feeling of uncertainty that caregivers experience during hospitalization is examined in few studies. Our study's findings are similar to those of Stratton⁵ and Solan et al,⁶ who found that parents

deal with fear and must cope with uncertainty during their child's hospitalization. In our study, the uncertainty is derived from the BRUE diagnosis and the uncertain cause of the events. Other studies in which the authors examine unexplained medical conditions reveal that parents desire an etiology for clinical findings and that having unexplained symptoms leads to the perception of having more complex needs, which is associated with increased anxiety.^{19,20} Although many parents can understand that there is uncertainty in medicine, they emphasize the need for clarity in communication, for engagement with health care providers, and for access to resources to help with coping.²¹

The way that medical providers discuss uncertainty also matters. Bhise et al²² showed that parents prefer that physicians imply uncertainty by presenting it with broad differential diagnoses as opposed to saying that they are not sure. This is reflected in our study, because caregivers noted their discomfort with a diagnosis that was described as unexplained. In line with discussing a broad differential diagnosis, providers could reassure families by discussing how serious conditions are low on the differential on the basis of the infant's symptoms. Previous research on parent-physician communication and medical information giving reveals that understanding a caregiver's internal thought process can help providers frame their conversation.²³ If providers can personalize conversations to address caregiver-specific concerns, then some of the feelings of uncertainty and hesitancy about being discharged from the hospital may be alleviated.

Addressing Discharge Readiness

Studies on discharge readiness have revealed that caregivers have conflicting emotions of relief provided by a child's clinical improvement and of anxiety over lingering concerns with discharge,⁶ which is also illustrated in our findings. The general sense from caregivers in our population was that they felt more confident about their ability to observe their infants at home after monitoring in the hospital but still felt a little fearful of the uncertainty of not

knowing the prognosis for their infant. The caregiver's remaining trepidation was explained as a feeling innate to parenthood; research has revealed that "emotional discharge readiness" and parental intuition are factors in discharge readiness.⁶ Research has also suggested that parental unease about the transition home could be mitigated by communication after discharge, which has been shown to decrease readmission.^{6,24,25} For example, phone calls to a family at home could be especially helpful for parents of patients with higher-risk BRUE given the degree of ambivalence about discharge.

Anticipatory guidance from physicians is a cornerstone of the discharge process, and it is especially important in the setting of BRUE to address the "what ifs" after discharge. In the study by Solan et al⁶ on hospital-to-home transitions, the authors also emphasize the desire that caregivers have for information to care for their child. In our study, CPR training was 1 tool that was used to address this desire. Further research is needed to see whether additional educational interventions focused on anticipatory guidance can help prepare caregivers for recognition of red flags of cardiopulmonary compromise or seizures. Additionally, the role of skilled communication and multimedia, disease-specific education is alluded to in previous studies on discharge readiness and can be a potential area for improvement among providers.^{25,26} Caregivers could also benefit from a unified language to describe BRUE by using resources through the AAP, which include an educational handout for parents with answers to commonly asked questions about BRUE.²⁷

Limitations

This study has several limitations. First, we only interviewed English-speaking caregivers; in doing so, we excluded possible perspectives related to communication with the medical team or to cultural differences in experiences with a child's hospital stay. Despite this limitation, the sample group reflects a wide diversity in race and educational background. Second, our study was conducted at a single institution; however, our admission criteria

were in line with the AAP guideline in identifying higher-risk BRUE and were thus generalizable because we likely see an acuity of BRUE similar to that seen by other institutions that follow the guideline. Third, the previous experience of caregivers of our patient population could differ from that of caregivers in other settings because of the medical complexity of infants in our center, with one-third of infants having a history of previous hospitalizations. Furthermore, in light of recent research by Meyer et al,²⁸ in which the authors suggest that some patients are initially misdiagnosed and may not meet all BRUE criteria, we must acknowledge as a fourth limitation that we relied on chart review to determine if ongoing symptoms were present at the time of presentation because it was not feasible for the research team to be present during the time of admission. Fifth, we do not account for providers' input in this study. Our understanding of what discussion occurred between caregivers and their medical teams only comes from what caregivers mentioned in their interviews. Finally, qualitative methodology allowed for potential researcher bias; however, the use of 2 coders allowed for greater reliability and trustworthiness. Participants may have also provided socially acceptable answers during interviews and may have felt uncomfortable with being forthright, especially when discussing sensitive topics.

CONCLUSIONS

In this study, we describe the hospitalization experience of caregivers with infants admitted for BRUE using semistructured interviews. Our findings reveal the hospital experience for caregivers, includes elements of reassurance but still ongoing feelings of uncertainty and conflicting emotions about the discharge from the hospital. Caregivers' perspectives and the experiences of their infants hospitalized for BRUE can be used to identify opportunities to improve the hospital experience and address their discharge readiness.

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