

But What Was “It”? Talking to Parents About BRUE

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There has been a paradigm shift in pediatrics. In 1986, the concept of “near-miss sudden infant death syndrome” was replaced by the term “apparent life-threatening event” (ALTE).¹ The goal was to clearly distinguish that which was uniformly fatal—sudden infant death syndrome—from that which was seldom so. Thirty years later, research has shown that ALTE is rarely life-threatening. Two prospective studies involving >1100 infants with ALTE found no mortality during hospitalization or within 72 hours of discharge from the emergency department.^{2,3} Thus, the terminology has changed again, and the concept of ALTE has been retired by the American Academy of Pediatrics (AAP). Now called a “brief resolved unexplained event” (BRUE), the wording is purposeful in its intent to highlight the benign nature of these events.⁴ Regardless of what they are called by clinicians and researchers, these events remain frightening and anxiety provoking for parents and caregivers. That is, after all, why they seek care for their infant.

Now, when infants come to medical attention after these odd events, clinicians call it a BRUE, which is exactly what the name implies: a transient alteration in an infant’s color, tone, mental status, or breathing whose etiology remains unclear after a detailed history and physical examination. These well-appearing infants are classified in the AAP clinical practice guideline (CPG) as being at lower or higher risk on the basis of patient and event characteristics. Those categorized as lower risk are extremely unlikely to have a recurrent event or a serious underlying diagnosis, so the CPG does not recommend broad diagnostic evaluation or routine hospitalization. The CPG does not make specific management-related recommendations for patients classified as higher risk.⁴ The move toward limited diagnostic evaluation and away from hospitalization signifies a shift from the historical approach to these patients, in which diagnostic evaluation was varied and hospitalization was common.⁵ Although clinicians are eager to optimize care for these infants and are incorporating the CPG into their institutional clinical care pathways, parents may be more reluctant to embrace the minimalistic approach advocated by the AAP. Yet, the concerns and expectations of caregivers have not really been explored.

In this issue of *Hospital Pediatrics*, Khan et al⁶ address this gap in the literature and provide insight into parents’ perceptions of a BRUE. In qualitative semistructured interviews exploring parents’ experiences with hospitalization after a BRUE, the authors identify that parents find hospitalization reassuring yet struggle with the uncertainty

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inherent in the diagnosis of a BRUE. Consequently, parents were ambivalent about being discharged from the hospital as they tried to balance their relief that no serious underlying diagnosis was identified with their worry that the event might recur.⁶ Collectively, these findings provide clinicians with important insights that could help shape their conversations with families regarding BRUEs.

Central to parents' angst is concern over the unexplained nature of the event. As a parent stated, "I'm still gonna walk out of here a little iffy and confused on what really was it."⁶ Parents, unfortunately, are not the only ones who are confused. Thought to reflect infant immaturity, the exact pathophysiology of these events remains unclear. As a result, ALTE and now BRUE describe a constellation of symptoms packaged as a diagnosis. Although research helps clinicians explain to parents what a BRUE is not, health care providers cannot yet say with certainty what it is, leaving parents to fear that "one day...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."⁶ Rational or not, on the basis of the evidence, acknowledging these fears and framing the conversation with parents about BRUEs around these insecurities should be an important part of the dialogue. By shifting the focus away from what is unexplained to what is known—that the condition is not life-threatening and a serious underlying diagnosis or recurrent event is extremely unlikely—may help to decrease parental anxiety.

The feelings of unease reported by the families to Khan et al⁶ were offset, in part, by the reassurance afforded by hospitalization. Parents indicated that hospitalization provided a sense of safety and security because diagnostic testing helped "put this issue to rest," and hospital monitoring enabled parents to "feel like they're really watching" their infant.⁶ An important limitation of this study, however, is that all of the subjects were parents of hospitalized infants who were categorized as having a higher-risk BRUE. What about parents of infants categorized as lower risk,

for whom testing is not indicated and hospitalization is not warranted? And where does this leave the parents of higher-risk infants who seem well enough to be discharged home from the emergency department? As research untangles the issues of the higher-risk group and the relative contribution of individual factors in determining risk becomes clearer, recommendations may begin to lean toward a more conservative approach for a subset of higher-risk patients as well. Thus, as we move away from evaluating and admitting the majority of infants with BRUEs, further work is needed to understand how a similar level of reassurance can be provided to caregivers without the testing and monitoring valued by parents.

At the conclusion of a medical encounter for a BRUE, our goal as clinicians is to help parents "feel ready to go home...relieved because nothing's wrong."⁶ This study highlights that parents feel safer in a medical setting⁶; thus, discharge instructions are an important component of empowering parents to care for their infant at home. In the case of BRUEs, further study is needed to better understand the usefulness of the discharge instructions advocated by the CPG. Parental anxiety may actually be heightened by some of the elements included, such as follow-up within 24 hours with the primary care provider and access to resources for cardiopulmonary resuscitation (CPR) training.⁴ Pediatricians should advocate for CPR training for parents and caregivers as a general public health measure, and literature suggests that CPR training does not increase caregiver anxiety.^{7,8} However, those studies were conducted with families of patients at very high risk of cardiopulmonary collapse.^{8,9} When discharging infants with a benign condition that parents still fear is life-threatening, it is possible that for some parents, simultaneously providing resources for CPR training undermines the message that their infant is "fine." Furthermore, encouraging families to seek an urgent follow-up appointment with the primary care provider underscores the seriousness of the event. Health care providers need to be cognizant that these mixed messages may impede

clear communication with parents about the benign nature of a BRUE.

As our understanding of BRUEs continues to evolve, the results of this study by Khan et al⁶ highlight that a key component of the care provided to patients and families after a BRUE focuses on the parent, but how to best meet their needs remains unclear.

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