A growing body of outcomes research has demonstrated that a child's serious illness can have long-term physical and mental health sequelae for both the child and his or her family.1 These findings have repeatedly been identified in surveys and family interviews, most often after discrete illness and hospitalization encounters.2 For children with lifelong, debilitating conditions, the results of these family interviews are even more compelling.3 What remains less well understood are the practical implications of these findings; to what extent do these sequelae result in measurable changes in health status for the individuals experiencing them? Feudtner et al4 address this question using a large commercial health insurance claims data set to compare the health care encounters, diagnoses, and medication prescriptions of US families of children diagnosed with 1 of 4 types of pediatric life-threatening conditions (LTCs) with those among families of matched controls. In the cohort of more than 25,000 families, Feudtner et al4 found that case mothers, fathers, and siblings had higher rates of health care diagnoses and utilization compared with control families, and this pattern was even more pronounced among families of children whose LTC was associated with chronic illness and debilitation. Although prior studies have examined the consequences of pediatric LTCs in small family cohorts,5 the use of a large insurance data set permitted Feudtner et al4 not only to assess multiple domains of health and health care use but also to directly compare thousands of case families with control families. The results of this analysis suggest an association of pediatric LTCs with family members' mental and physical health outcomes beyond the normative US family experience, which has many baseline stressors. Furthermore, Feudtner et al4 examined these outcomes among all family members, including siblings, for whom there is a particular paucity of literature.

For pediatric health care professionals caring for children with LTCs and adults caring for their family members, these findings suggest moving beyond the isolated health considerations of the child with an LTC and considering the interdependency of mental and physical health outcomes of each member in a family unit. Children with LTCs depend on their parents to manage both their physical and their emotional health needs, but parents providing this care can experience marked traumatic stress from fearing their child may die and watching him or her struggle with illness while managing accompanying logistical and financial stress. Traumatic and chronic stress lead to deterioration in parents’ mental and physical health through biological mechanisms and the individuals’ reduced focus on managing their own wellness and chronic health conditions.6,7 These effects on parents’ mental and physical health, in turn, may affect their ability to optimally manage their child’s physical and mental health, leading to poorer health outcomes for the child.8 Although this prior work6–8 documents the association of a child’s LTC with their parents’ health, Feudtner et al4 reported that posttraumatic stress was experienced nearly equally among parents and siblings of pediatric patients with an LTC. This finding indicates that clinicians should consider how the possible large array of effects on families of children with LTCs are being screened for, discussed, and managed in longitudinal health care settings. Specifically, data from the study by Feudtner et al4 highlight the importance of a trauma-informed care approach, in which screening for anxiety, depression, and signs and symptoms of posttraumatic stress for adults and children in the family is integrated into routine care.9 An approach such as this is well supported by literature demonstrating the similarities between the posttraumatic stress experienced by families after natural disasters and by those that have been exposed to serious illness or injury.10 The more often that data like these can be used to normalize the experience of trauma after the diagnosis of a serious, life-threatening illness in a child, the more often families and clinicians will have the opportunity to openly discuss the signs
and symptoms of posttraumatic stress and the potential need for medical management of these conditions.

For researchers, the article by Feudtner et al4 may provide an anchor for future research to examine the types of logistical, financial, emotional, and health supports that families of children with LTCs require to improve the physical and mental health outcomes for all family members. Data sets such as the one used by Feudtner et al4 that provide insight into the health care experience of all family members in multiple domains (inpatient, outpatient, and pharmacy claims) will likely be critical to these lines of inquiry because they offer insights based on multiple years of data with relative time and cost efficiency. A challenge yet unaddressed is the effect of LTCs on families with public insurance or no insurance at all. The complexity of identifying physical and mental health effects among families with lower socioeconomic status, lesser social and financial resource networks, and less access to many forms of health care cannot be overstated. However, it is equally important to unequivocally state that these effects must be quantified so that they can be addressed as the public health imperative that they are.

As with many large-scale epidemiologic studies, the study by Feudtner et al4 raises additional questions that cannot be answered here. Perhaps most importantly, the study is a call to action for all who care for children with LTCs because there must be a clinical and research paradigm shift from simply considering the child with an LTC to considering the entire family unit surrounding that child, whose health and well-being as an entire unit will be essential to the health and well-being of each of its members.

ARTICLE INFORMATION
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REFERENCES

