



## Anticipatory Guidance on the Risks for Unfavorable Outcomes among Children with Medical Complexity

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Recent decades have seen profound improvements in the care and survival of children with medical complexity, that is, children with complex chronic conditions (CCC) and functional limitations, who require substantial and ongoing medical and community-based care.<sup>1</sup> Nevertheless, many of these children remain at disproportionate risk for unfavorable health-related outcomes as the result of their medical fragility and prodigious care needs. These outcomes include, but are not limited to, acute-on-chronic illness, hospitalization, and unexpected death. Understanding these risks as a provider is essential to avert those risks that are preventable and to anticipate those that may not be preventable. Likewise, families of children with medical complexity need to be informed beforehand about these potential risks. Such preparation can be considered a form of anticipatory guidance for these families and should be a basic part of optimal care for this vulnerable population.

For those caring for the general pediatric population, anticipatory guidance is a familiar educational practice that seeks to proactively prepare families for what they should expect in the future and how to meet the child's needs at her current/next developmental stage.<sup>2-4</sup> Common topics focus on well-child and preventive health, including feeding, sleeping, growth, immunizations, safety and accident prevention, behavior, puberty, and sex education. Parents have reported increased healthcare satisfaction when anticipatory guidance is provided.<sup>5</sup> Understandably, some topics need to be modified for children in different circumstances or settings. Similarly, for the families of children with medical complexity, anticipatory guidance is equally important; however, the topics require adaptations and additions to be germane because the complex child's developmental and medical trajectories may be significantly different than those of the typical child. Among other topics, anticipatory guidance for families with children with medical complexity should include information on their risks for unfavorable health-related outcomes.

Characterizing the risks of this heterogeneous population was perhaps first attempted in earnest at the turn of this century, when several insightful investigators started publishing groundbreaking research on these children and the impact of their chronic conditions. The first was the seminal study by Feudtner et al<sup>6</sup> of pediatric deaths in Washington State between 1980 and 1997 attributable to underlying CCCs. Their report highlighted that although rates of pediatric mortality were declining, the proportion of deaths due to CCCs were substantial and growing. Importantly, the report by Feudtner et al also

gave us terminology to collectively conceptualize these patients' severe chronic conditions and a method to identify them.

Although the study by Feudtner et al and subsequent reports<sup>7,8</sup> highlighted the increased risk of mortality among children with CCCs, Dosa et al<sup>9</sup> focused on their high risk of severe acute illness. Prospectively studying a 17-county region in upstate New York, they determined that children with chronic conditions had a more than 3 times greater risk of unplanned admission to the pediatric intensive care unit compared with children without a chronic condition. Furthermore, children dependent on various medical technologies, such as mechanical ventilation, tracheostomy, intravenous medications or nutrition, tube feeding, and implanted cardiac pacemakers, had a more than 300 times greater risk. Almost one-half of these admissions were estimated to have been related to the children's chronic conditions. Although some of these admissions were considered preventable, most were characterized as unavoidable. These early studies conveyed what providers undoubtedly were observing in their hospitals and clinics—children with medical complexity were a growing group of vulnerable children with risks that far exceeded those of children who were not medically fragile.

Since then, numerous investigators have studied children with medical complexity and their increased risks for severe illness, hospitalization, and death. One such study by Havers et al<sup>10</sup> focused on children with neuromuscular and neurodevelopmental disorders, a relatively large group of patients that often meet criteria for being medical complex, and their risks for severe respiratory infections, which are a frequent cause of acute illness among children with medical complexity. Using a sizeable cohort drawn from multiple states, Havers et al compared the rates of respiratory infection-related hospitalization among children with neurologic disorders with those of the general pediatric population. They found that 12% of hospitalizations of children with neurologic disorders were for respiratory infections; one-quarter of these hospitalizations were repeat respiratory hospitalizations among less than 4% of these children. Children with neurologic disorders had a more than 5 times greater relative rate of respiratory infection-related hospitalization than the general pediatric population. Children with specific neurologic disorders, such as cerebral palsy, muscular dystrophy, motor neuron

CCC      Complex chronic conditions

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diseases, degenerative diseases, metabolic diseases, and chromosomal disorders, had even greater relative rates of hospitalization. Relative rates of death during respiratory infection-related hospitalizations were likewise substantially greater among children with neurologic disorders.

Although this study did not delineate the various infectious etiologies of these severe respiratory illnesses, they undoubtedly included an array of common organisms that lead to upper respiratory tract infection, tracheobronchitis, and other nonsevere respiratory illnesses in most children. The study by Havers et al supplements a growing body of literature that has found increased infection-related risks among children with severe chronic conditions<sup>11-13</sup> and dependency on medical technology.<sup>14-16</sup> These studies also underpin the importance of routine and annual immunizations for children with medical complexity to decrease infection-related risks.<sup>17,18</sup>

Although infection is a major reason why children with medical complexity become acutely ill and need hospitalization, it is certainly not the only one. They are likewise susceptible to noninfectious respiratory insults, hemodynamic instability, metabolic derangements, gastrointestinal dysfunction, seizures, autonomic imbalances, and so on. Many of these children have multiple bouts of acute illness or exacerbations that require numerous hospitalizations.<sup>19</sup>

Once hospitalized, their recovery from acute illness often is complicated and protracted. Children with medical complexity have longer lengths of stay,<sup>20,21</sup> greater use of intensive care,<sup>22,23</sup> and more adverse events<sup>24-27</sup> than most children. Beyond the risk for symptomatic disease, children with medical complexity are at disproportionate risk for in-hospital, sudden, or unexpected death.<sup>28-35</sup>

As outpatients, children with medical complexity are at greater risk for adverse drug reactions and drug errors because of the high number of prescription medications they require. Although not directly related to their underlying conditions, their high level of dependence on the care of others also put these children at risk for abuse and neglect.<sup>36-38</sup>

As part of good care, providers are obliged to understand the risks their patients carry and to help their families anticipate and prepare for the range of possible events that they may encounter. For children with medical complexity, proactively providing anticipatory guidance means offering tailored, culturally sensitive information about what unfavorable health-related outcomes could happen to the child. Doing so in a measured manner helps ensure they are well-informed and can supplement psychoeducation of the family. Psychoeducation is a related concept to anticipatory guidance; it seeks to provide information to empower, relieve uncertainty, and enhance psychosocial adaptation to the illness at hand.<sup>2,39</sup> For example, a family of a child with profound cerebral palsy and static encephalopathy should know that the child is still at risk for hospitalization due to a common respiratory viral infection and that such misfortunes do not belittle their meticulous home care.

The responsibility of providing this anticipatory guidance falls on those providers who direct the child's overall care and have a longitudinal relationship with the child and family, as

well as any provider who has significant interactions with them and insights into their pertinent risks. Such providers often include primary care physicians, complex care providers, and specialists.

Anticipatory guidance on risks for unfavorable outcomes is best introduced early and during periods of stability—that is, soon after diagnosis and before a crisis, such as acute-on-chronic critical illness. When families are completely unprepared for even the possibility of a crisis, the crisis may be even more traumatic<sup>40,41</sup> and may make necessary decision-making all the more difficult. When the trajectory of a child's underlying condition and/or treatment is known, anticipatory guidance should be provided at appropriate antecedent points. Providers periodically should reinforce and expand on pertinent points during longitudinal care. Considering that the trajectory of the child's underlying disease is not always known and crises often cannot be predicted, other potential opportunities include when the child starts to be left in the care of others, the development of a new comorbidity, before surgical procedures, the death or critical illness of another child the family knows, and other transition points. Anticipatory guidance and psychoeducation also should be given or reinforced after a crisis (ie, before hospital discharge and during post-hospital visits), given that such crises may increase the family's readiness to hear this guidance. Thus, the responsibility of providing anticipatory guidance also falls upon acute care providers, such as hospitalists and intensivists.

Notably, anticipatory guidance on disproportionate risks of unfavorable outcomes is not prognostication for the individual child, and conveying it as such may frustrate the family-provider relationship if erroneous predictions are made. In addition, families should not be overwhelmed with information on all the possible "bad things" that might happen to their child. If their child has never been severely ill, asking a family to absorb a long list of possible unfavorable outcomes that might happen can be disorienting and without context. Overemphasizing the child's risks also can make families believe that they are "on a different page" from providers and obstruct the family-provider relationship. By addressing these topics belatedly or in a manner that is not forthright, however, providers risk underinforming families.

Although providers may view these risks as simmering threats to the child's well-being and want families to acknowledge the possible negative outcomes, families may view them as mere possibilities that need not be dwelled on until they happen. Thus, providers must balance the need to be sensitive with the need to be forthright. They should explain to families that it would be inappropriate for them to keep information and concerns from them, that they are obliged to sometimes discuss difficult topics, and that these certain topics increasingly will need to be addressed as the child's medical trajectory changes or becomes more clear. Then, providers must be able to gauge the family's readiness to receive information on these topics. A family's readiness to accept information on their child's risks for unfavorable outcomes may be enhanced by integrating anticipatory guidance and psychoeducation on other topics pertinent to their child. These include medical (eg, progressive

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