

The Pediatric Parent

by Jennifer DePeters, M.A.

The pediatric patient presents complexities for a patient representative. Legally, unless the pediatric patient is eighteen years of age, married, or emancipated, the patient's parent is the legal decision-maker. This does not mean, however, that health care professionals and parents do not provide the young patient information, nor consult him or her in decision-making. In many cases, the patient is able to understand information and may even realize death is the prognosis. Nevertheless, this writer's experience as a patient representative is such that when someone mentions the words pediatric, infants' unit, or children, the image of a parent at bedside, more often hovering over the bed, thus obscuring the patient, is immediately what comes to mind. You can be sure the person standing next to the bed is the one calling the shots, thus the health care decision-maker.

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Perhaps, what follows is of some assistance for patient representatives, especially since staff looks to us professionals when a patient's parents are interfering in the rendering of care. An intensive care nurse once remarked during a particularly high incidence of traumas, "I can do the technical, complex clinical care of this child, but I cannot perform my duties with this parent here." Often, the staff feels as though the parents are interfering with care when they are standing at the bedside and asking questions. It is critical during times like these to consider the parent's position with respect to what is happening to the child before banning the parent from the bedside.

An easily dissected scenario examines this parental position. One of the most common yet challenging situations arises when a pediatric patient's symp-

toms seem to be gastrointestinal related, one in which his or her eating habits and schedule are affected. There is an added layer of anxiety for not only the child, but more expressively and prominently, for the parent. This added layer of parental anxiety can be attributed as follows: parents, whatever their parenting skills, regardless of class, education, or age, know food. One form of love and concern that is easily expressed is through feeding the child. Health care professionals often will delay, suspend, or deny eating and fluid intake. Parents, regardless of whether these activities are at the root of the problem or aggravating the symptoms, insist "this not eating business," or in the clinical world, "NPO status," end as soon as possible. Delayed tests, often ultimately rescheduled, can add to parental anxiety, not just for the inconvenience, but because the child may

have needlessly been deprived of food. To be fair, a child, who knows his or her parent can be counted on for nourishment, will be looking for that bottle, Cheerios, or juice, assuming this expectation to be met. That inquisitive, puzzled look on a child's face is difficult for parents to ignore and deny, especially if the child is otherwise healthy and just undergoing a diagnostic or routine test. Needless to say, even if a child is too sick to want food, when a parent gives him or her food (nourishment and love), this brings a feeling of normalcy, and specifically control for both child and parent in an otherwise out-of-control hospitalization, disease, or diagnosis.

In summary, this one piece of normalcy has been taken away from a child, and more importantly, from a parent. Not only will the child be confused from this deprivation of food, but also the parent is left feeling out-of-control by this role deprivation.

Is it that strange, then, for a parent with a child who may be on a ventilator and deeply sedated, to start questioning how the child is being nourished? The

tubes, the buzzing and beeping of the high-tech machinery, may be beyond comprehension for a parent in crisis. How the child is being fed, a basic need of everybody's life, is somehow the only aspect of the care being provided that a parent may question.

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There is no magic answer or catchall reply that a health care professional, us included, can offer. Certainly, thorough explanations, when the time is right, helps; "When I am finished doing such and such, I'll explain how your child is being fed or why we cannot start hydration." References to the parent's role or including him or her in the technical administration of nourishment, however small the parent's part, can add a sense of control and normalcy in this most unnatural setting. Patient representatives can deflect some of the anger that is being focused on the medical provider. This writer's favorite response to the badgering parent who needs to leave the area, if only for a brief period, is, "Help us help your child."

Staff depend on us to not just assist in the support of the pediatric patient, but also to be the voice of the patient, or in this case, the parent. Our quick response to the bedside can offer a more reasonable solution in determining why a parent is reacting a certain way. Specifically, knowing why parents focus on certain aspects, such as eating, can be helpful in calming down parents and getting parents' questions answered. Ultimately, the patient representative, by assisting parents and staff, aids the pediatric patient, even if the patient cannot tell us that.

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