Working with Families Perceived as Difficult

David Buxton, MD; Sandra Clancy, PhD; and Patricia O’Malley, MD

In 2009, there were 6.4 million hospital stays for patients aged younger than 17 years, accounting for 17% of all US hospital inpatient care. The average length of stay was 3.8 days. An estimated 150,000 to 200,000 of these children require pediatric intensive care units (PICU) due to the severity of their illness. Research has shown that the PICU experience is not only stressful for children but also their families. Mothers have been noted to perceive their family functioning as dysfunctional even up to 6 months after discharge from a hospital. In a study of parents whose children recently had received a cancer diagnosis, 40% of fathers and more than 50% of mothers met criteria for acute stress disorder.

In addition, fathers and mothers have been found to have poor concordance in assessing their seriously ill child’s psychosocial health, emotional function, communication, and cognitive fatigue. This difference can lead to family discord. A combination of these factors may account for frustration and anger toward each other and hospital staff. It has been noted that 68% of nurses have been verbally abused by a patient’s family member. Even when relationships are challenging, pediatric health care providers must work with families to ensure high-quality care to their children.

Another contributing factor to ten-

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sion in the PICU is that the multidisciplinary team approach to inpatient pediatric medical care is often characterized by tight schedules, rotating team membership, and a range of departmental and institutional politics that can blur professional boundaries and impact care. Lack of communication between care team members about patients can hamper collaboration and even lead to inadequate pain management.

CASE PRESENTATION

Natalie is an 11-year-old female with a medical history of poorly controlled asthma who had an asthma attack that led to a subsequent acute cardiac arrest at home. She was transferred to a tertiary hospital PICU from a rehabilitation facility several months after her cardiac arrest, for management of severe dysautonomia, or “storming,” and a persistent vegetative state.

The patient’s family members, who were not fluent in English, included her mother and two aunts who provided Natalie with constant bedside attendance. They quickly began to voice anger at and distrust of Natalie’s medical team due to the rotating schedules of the PICU staff and subspecialists. Simultaneously, PICU staff expressed their frustration to each other at what they considered the family’s willful refusal to accept Natalie’s prognosis, as well as what was perceived as the family’s insistence on a miracle.

Whenever Natalie’s symptoms escalated, family members would often become agitated. Their expressions of anger reduced several staff to tears; some even declined to be part of Natalie’s care team. Morning bedside rounds were often disrupted by family members’ hostile and denigrating comments that heightened tension among house staff as Natalie’s potential for meaningful recovery was limited and her storming seemed to be uncontrollable.

Natalie’s mother identified a few nurses whom she felt were “on our side” because they had allowed the family to adjust cooling blanket equipment and place an additional cot near Natalie’s bedside. Staff members who attempted to reset limits because of safety concerns were labeled by the family as “no good.” One morning during rounds, Natalie’s family demanded the patient be transferred after they had heard the term “persistent vegetative state” used by the team to describe Natalie’s condition; they declared that the patient’s care team could not treat her if they believed she was “a vegetable.” A team meeting was held to discuss the case.

FACTORS IN ADVERSARIAL RELATIONSHIPS BETWEEN FAMILY AND CARE TEAM

It is helpful for members of PICU care teams to meet and review a patient’s case in order to discuss issues that commonly contribute to difficult interactions. In Natalie’s case, her family was perceived as challenging for the care team for many reasons. Specifically, their restricted ability to communicate in English, cultural barriers, uncontrolled symptoms (storming), misunderstanding of treatment options, and extended stay in medical facilities contributed to a challenging environment for care.

Sometimes there are contributing factors that interfere with optimal patient care (see Table 1). Many of these obstacles cannot be resolved by the treatment team; but identifying them as potential problems can help the care team — and the families — develop strategies and assist with locating the resources necessary to address them. In addition, awareness of these factors can facilitate more productive relationships with family members when diagnosis, prognosis, and treatment recommendations are discussed.

<table>
<thead>
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<th>TABLE 1. Confounding Care Factors</th>
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<tbody>
<tr>
<td>• Language barriers</td>
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| • Cultural and religious differen
ces                                |
| • Acute onset of a child’s illness |
| • Perception by a parent of the
cild’s suffering and pain level    |
| • Misunderstanding of treatment or diagnosis |
| • Heightened physiologic stress on family of prolonged bedside care; includes deteriorating self-care (inadequate sleep, poor nutrition, inconsistent hygiene, etc) |
| • Unclear etiology of child’s illness |
| • Previous negative experiences with medical care |
| • Multiple providers with poor communication amongst team members |
| • Psychiatric illness amongst family members |
| • Financial problems             |
| • Transportation issues         |

POTENTIAL OBSTACLES TO CARE

Bringing the entire patient team together can help create a more comprehensive portrait of a family and identify the potential conflicts to providing them with optimal care. In Natalie’s case, grief and difficulty accepting the likely outcome of the patient’s status were held by both the primary care team members and family alike; however, because there was a lack of communication, the family and members of the care team did not realize how much they had in common.

To facilitate communication between Natalie’s family and care team, staff from the social work, chaplaincy, child life, child psychiatry, and pediatric palliative care departments were asked to become more involved in her treatment. The family was encouraged to contact specific primary medical staff members when they had a concern, and interpreter services were used to augment communication.
After this meeting, it became clear that the team needed a new focus that highlighted improving the family’s experience of care in areas not related specifically to Natalie’s medical treatment. A team captain was designated, and meetings with all team providers were held twice a week to ensure clear communication. The consulting services helped the care team and family explore and express their difficult emotions instead of acting on them in a destructive way. This process allowed Natalie’s family to begin grieving their loss while feeling supported.

**IMPORTANCE OF CLEAR COMMUNICATION**

Natalie’s initial team meeting was only the first step in forming an alliance to avoid conflict between staff and families. It is essential when working with families perceived as difficult for team members to make every effort to keep the message uniform and clear at all times. Families can interpret conflicting information from staff members as poor care or, even worse, incompetence. For example, in Natalie’s case, her continual storming led to a need for constant testing depending on her ever-changing status; this was frustrating and confusing for her family.

A useful strategy to ensure staff and families understand the current treatment plan is to hold multiple daily “team huddles.” These informal conversations can allow bidirectional communication among all parties and provide explanations about any confusing aspects of care. Staff should make an effort to enumerate what is currently being done for a patient, especially if the benefit is not apparent: for example, providing oxygen to ensure appropriate saturation rate, monitoring pulse and rhythm to check heart condition, etc. This is especially important if families articulate that “nothing is being done to address all the medical problems.” If a care plan changes, the daily meeting offers an opportunity to provide information to the family and reassure them that their concerns are being addressed. In addition, these meetings can help clarify providers’ job descriptions so that parents can make the right choices about whom to present their specific concerns.

**ANTICIPATION OF COMMUNICATION DISRUPTIONS**

It is important to designate a “captain of the ship” to take charge of the treatment plan and facilitate conversations and decisions among providers. Staff should make an effort to enumerate what is currently being done for a patient, especially if the benefit is not apparent.

In Natalie’s case, multiple consults were being conducted to help manage her difficult illness. Each specialist had a unique understanding of the nuances of Natalie’s illness; prior to the creation of the team meetings, these points of view were being articulated to her family whose comprehension was quite limited. Unfortunately, consults were then being reported to PICU team members who were rotating through service, leading to further confusion and frustration, especially on the family’s part. The ultimate blow to the family’s will to cooperate was when Natalie was described as being in “a persistent vegetative state.”

This could have been avoided had Natalie’s treatment team discussed standardized terminology among themselves and the family. The lesson learned in this case was that by designating a “captain,” all medical information can be aimed at one person who can then interpret ongoing recommendations, appropriately direct care and ensure all providers understand the treatment plans.

**MINIMIZE ATTEMPTS TO “SPLIT” CARE TEAM**

Staff should be aware of a family’s attempts at “splitting” of caregivers. Natalie’s presentation demonstrates how conflict among providers and families can lead to negative outcomes such as staff being upset enough to request transfer off a patient’s case. A culture of conflict in which providers feel judged or inadequate can affect their ability to provide optimal care for a patient. Inherently, a split can arise between staff who agree to follow a family’s directives in order to avoid harsh treatment, and those who set limits despite any verbal abuse from the family. In Natalie’s case, if staff allowed the family control over her cooling blanket and a bedside cot, they were seen as “on our side,” but if they set limits were “no good.”

To help minimize attempts to split the care team, “partnering up” with a colleague can help providers feel more supported when interacting with upset family members. This principle was especially important for Natalie’s care as it was noted her families’ agitation corresponded with her storming, which needed immediate attention by staff. By partnering up, one staff member can provide moral support for the provider administering care while simultaneously helping to calm family members.

Splitting also can be prevented by having a clear strategy on how to deal with denigration of other team members, including expressing sympathy if things “did not go as well as hoped”
while reinforcing respect for another team member’s capabilities to perform a duty. Staff can name and validate feelings of frustration, distress, and disappointment about an event without placing blame on anyone.

**PROACTIVE APPROACH**

Another useful tool for staff is proactively to identify brewing questions or concerns from a family. Usually it is the nursing and nursing assistant staff that spends the greatest amount of time with a patient; they can alert other providers of perceived issues with treatment. If a family seems to have constant questions, it may help to establish structured times for questions or visits to minimize frequent or demanding inquiries. This plan can help the nursing staff manage families and minimize disruption from ongoing family requests.

**REINFORCE NATIVE PARENTING**

Finally, providers should support families in their native parenting roles. Because it can be difficult for parents to allow other people to perform daily routines with their children, it is helpful to encourage families to nurture and comfort as they would do in a nonmedical setting. If appropriate, staff can include them when providing basic care, such as changing diapers, bathing, and feeding. This collaboration can ease tension as parents feel part of the team instead of against it. To enhance the bond between providers and family, team members also can encourage parents to talk about their child’s personhood, asking parents to share photos of the child before hospitalization, what music the child likes, what stories they like, and so on. This process allows families and providers to ensure no one feels a child “is a vegetable.”

**SUPPORTIVE RESOURCES**

As established during Natalie’s team meeting, services that are not cure-

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<td><strong>Strategy</strong></td>
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<tr>
<td>Clear Communication</td>
</tr>
<tr>
<td>“Captain of the ship”</td>
</tr>
<tr>
<td>“Stay on the same page”</td>
</tr>
<tr>
<td>“Who can answer that?”</td>
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<tr>
<td>Minimize Conflict</td>
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<tr>
<td>“Partner up”</td>
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<tr>
<td>“Provide information about work”</td>
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<tr>
<td>“Avoid the split”</td>
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<tr>
<td>“Pre-emptive strikes”</td>
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<td>“Help the parents parent”</td>
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<tr>
<td>Supportive Resources</td>
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<tr>
<td>“Experience of care”</td>
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<td>“Care of the team”</td>
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oriented are also important to the experience of care of a patient and their family. These services can include social work, chaplaincy, interpreter services, pet therapy, art therapy, child life, child psychiatry, and palliative care. By allowing families to have “nonmedical” caregivers involved, other forums are created to discuss topics which might be difficult for the primary care team to address such as the child’s prognosis, treatment options, and even potentially, imminent death. These consults are especially important when a prognosis is not hopeful, choices are ambiguous, or only the experience of care is left to be optimized. In addition, these services can assist providers who are feeling frustrated, burned out, taken advantage of, sad and/or angry. These emotions are common and should be shared in an appropriate venue to allow resiliency in the face of difficult choices and results.

MIRACLES VS. “BAD” OUTCOMES

Natalie’s story illustrates both the advances and limitations of our current medical treatment for patients. On one hand, she was able to survive her cardiac arrest, but on the other, Natalie’s storming could not be controlled with nonsedative treatment options. Commonly in these situations, families will shift to holding onto a hope for a miracle that often causes medical staff to disengage or become frustrated with them. However, staff can also understand this hope as an indication that a family recognizes that there are no further curative medical interventions available. When an expression of hope for a miracle occurs, it may be the first step in beginning to cope with an unbearable loss. By comprehending this viewpoint, staff can then join families in their hope for a miracle while also exploring what is within our expertise: “What would happen if a miracle does not occur?”

KEYS TO MANAGEMENT

As discussed, a few simple but effective strategies can be employed when working with perceived difficult families. Table 2 (see page 170) summarizes 10 tips to allow staff to ensure they are able to provide the best care to families during conflicts in care.

CONCLUSION

Families whose child is hospitalized undertake a difficult and stressful journey. Conflicts may arise between staff and families that can negatively influence treatment and create a difficult environment for care. It is essential to identify contributing factors, hold a team meeting to come to a shared understanding of the issues, consult appropriate services to assist in the experience of care, and find ways for staff to work with parents to ensure the best possible outcome for a child.

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