The Patient’s Family in the Pediatric Intensive Care Unit

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Introduction

The physical space of the pediatric intensive care unit (PICU) is usually filled with a symphony of sounds and noises that signify alarm situations. Tension reigns high amidst the hustle and bustle of activity as the staff cares for seriously and acutely ill children. Everyone associated with the unit lives and contends with this world of tension and learns to cope with the overabundance of stimuli. The young patients are dealing with their illnesses and their physicians as passive recipients of the treatment by the medical profession. In this chapter, we examine what happens to the families of the young patients; how the child’s illness affects them during the child’s stay on the unit; how this may affect them in the future; and the impact on the family dynamics between all of them as a result of the child’s stay on the PICU. We first explore what these families experience and follow up with suggestions as to how to help them deal with this. We then take advantage of this opportunity to deal with the “family” of health care workers in the PICU and, most important, to explore how to deal with the families who are both peripheral yet a central part of the PICU, namely, our own partners and children.

The Parents

Parents see themselves as the people who will protect their children, keep them from harm, and keep them safe from those who would hurt them. The greater the danger to the child, the less inhibited are the parents in their approach to defending them. Witness the mother who will attack the bear that holds her child in its arms!

When parents bring their child to the PICU, they surrender that child to the care of the personnel of that unit. Physical treatment of the child will often involve the child being pierced, cut, and manipulated in such a way that would be unacceptable to anyone else dealing with this child. On the unit, however, all too frequently this is entirely necessary to save the life of the child. The child is benefited psychologically by the presence nearby of the parents, who are there as a source of comfort and as a tie and bond to the natural family constellation [1]. This means, however, that all too frequently the parents are witness to the child being subjected to procedures that are uncomfortable and distressing to him. Anyone else who would do such things to their child would be severely challenged. Here, however, the parents must stand by and cooperate with the health care providers and hope that this will eventually bring their child back to health, and as protectors they would be able to take over once again as the parents. The parents are then forced into the position of being passive participants, able to help their child only through cooperating with the staff whose treatment is, in reality, visualized psychologically as an assault upon the child. As one parent pointed out, These people are being abusive of my child. They are doing to him something which he does not want to have done, which is not his choice, which is hurting him. They are holding him down and not giving in to his protests. Is this not abuse?

The parent whose child is in the PICU must, therefore, transcend the usual strengths required by a parent in order to deal with his or her children to reach a new level. In doing so, this would allow that parent to deal with those caring for the child in a spirit of acceptance and cooperation. The parents must resist the impulse to avenge the hurt being done to the child and to cooperate with the medical staff. They must trust this will help their child and that the child will grow to forgive them for not having protected them from the medical helpers.


Mother in the pediatric intensive care unit
Regression on the Part of the Parent

To deal with what is happening, the parent must retreat from the role of being the major decision maker and protector of the child. Parents need to give the leadership role over to the medical staff that are caring for and making decisions about their child. In addition, they give themselves over to hope and expectations and, not infrequently, to prayer and pleading of a higher being for the child’s health. High anxiety comes with the unknown factors involved with the child in the PICU. In many of these superimpose the presence or absence of blame on oneself and others, depending on the reason for the child being in the PICU. Now it is relatively easy to account for a temporary regression that may display itself to the PICU staff as excessive demanding, questioning their future activities, suspiciousness, hostility, and even untoward aggressiveness toward those caring for the child [2]. If not dealt with promptly and sensitively, this may lead further to complaints filed about the medical care and the personnel involved or, worse still, verbal or physical attacks upon the staff. One of the authors (S.G.) recalls such an incident where a child died as a result of complications following cardiac surgery:

I was sitting in their hospital room with the family who had come from South America. Although they had been initially almost speechless, after a few hours they were talking to me about the fact that they had been assured at home that if they brought their child to this particular hospital, their child would be cured of its disability. They would not have to worry about the cardiac surgery. We spoke of the frustration of this and examined where they might be feeling blame. Suddenly, father rose from his chair, approached the window of the hotel room, pounded on it, and yelled “It’s God’s fault, its God’s fault. God let us down.” Someone needed to be blamed, it needed to be verbalized, and hopefully the blame was best expressed against a being away from the unit.

The Issue of Blame

We live in a society where blame is an integral part of our belief system. If something has gone wrong, somebody, somewhere, is responsible. They are to be punished for, admonished for, or berated for what they have done to cause bad things to happen or for what they have not done in order to prevent bad things from happening. It seems that it is simpler to deal with overwhelming feelings when a source of blame is placed on a person or a thing. In this way, one does not have to face the impossible task of dealing with overwhelming feelings of helplessness in the face of an emotional onslaught. When one is incapable of doing anything to change one’s position, some comfort may, nevertheless, be gained from blaming others for the predicament in which they find themselves. This is a mechanism that is used by both adults and children in dealing with overwhelming emotional onslaught. When working with the family it is important to acknowledge to the members that this is a feeling that may be present. How to deal with these feelings is approached later in this chapter.

Unacceptable Feelings

Parents will often refer to their time on the unit as being like a nightmare. This may, in fact, be a good analogy. A nightmare is a situation in which one is horrified by being in a terrifying predicament and desperately looking for a way to get out. One way of extricating themselves from this nightmare is for the child to die. This is an unacceptable thought to most parents, yet the thought nevertheless does occur to them, even fleetingly. They are usually horrified by this, feel very guilty, and will do anything to keep their partner and others from knowing this thought. Yet, it is an entirely normal thought. In fact, this is a way of escaping the horrible nightmarish situation.

Bargaining

Many examples of bargaining exist, including parents who offer to give up smoking, to be more faithful in their marriage, to begin to attend church or synagogue regularly, to begin to operate more ethically in their business, to do more charity work, in return for their child’s recovery. When one is desperate and searching for any way to ensure the health of the child on the unit, parents will offer almost anything in return. This is a form of what we call magical thinking—an offering of psychological sacrifices in order to achieve what one hopes for. Parents will often think, however, if others find out what they were doing they will consider them to be weird or crazy.

Self-Deprivation

Frequently we have found that parents, while sitting in the child’s room or in the parents’ lounge of the PICU, feel that they are not allowed to enjoy any pleasure in life. These feelings vary and may exhibit themselves in various ways. For example, they may not allow themselves to go out for a good meal during the day or evening, to get a good night’s sleep, to go back home to be with the rest of the family for an evening, or to go to a movie during the hours when the child on the unit is asleep or unavailable to them. The parents feel as if any pleasure is something that is not allowed because it would be contrary to the experience that their child is going through. Often, they would not even allow themselves to think of anything lighthearted or humorous. They feel that anything that has given them comfort in the past is not to be allowed. The message, in essence, is, How can we enjoy anything at all while our child’s life is at risk—while our child is suffering and we cannot help?

The Siblings

The authors are unaware of any family that has within it more than one child where there is an absence of sibling rivalry. It is entirely normal for siblings to be competitive with one another and vie for the attention of their parents. When one child enters the spotlight within the family, the others are usually quite envious and often quite resentful of their brother’s or sister’s presence. Others in the family try to get more attention from their parents and gain their own share of the spotlight or favorite person. Frequently, these children even entertain unconscious or near-conscious thoughts about eliminating that sibling and taking the spotlight for themselves. When the sibling is ill and in the PICU, they are often fraught with guilt for having had such thoughts and feeling any resentment toward the child now having so much of the parental attention.

Now, not only is the child receiving all the parental attention but he or she is also using the very energy from mother and father who need to devote themselves to doing whatever they can to deal with the serious illness of the child. They might ask themselves, how could they as siblings demand anything of their father and mother when their needs are so trivial in comparison to those of their