Family Nursing Network

# The Family in the Intensive Care Unit: Living the Possibility of Losing a Child

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*This article represents an attempt to understand the family's experience of having a child admitted to a Pediatric Intensive Care Unit (PICU) and to identify the meanings that the family attributes to the experience of having a child in the PICU. The study used grounded theory as a research methodology. The data analysis gave meaning to the family's experience in the identification of the phenomenon of living with the possibility of losing a child, a phenomenon that involves family efforts to protect its members from family rupture or breakdown in the face of the life-threatening situation of the child's hospitalization. This phenomenon has relevancy in the daily practice of nursing as one explanation in understanding experiences of families in the PICU.*

***Keywords:*** *family suffering; illness experience; critical care; serious illness*

*Research questions*. How do family members define their experiences of having a child in a Pediatric Intensive Care Unit (PICU)? What are family members' behaviors during this experience?

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*Editor's Note:* A number of fascinating nursing studies that examine family experience in normative and nonnormative transitions are emerging from Brazil. Dr. Margareth Angelo, from the Universidade de São Paulo in Brazil, has provided strong leadership in family nursing in her country. Several of

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*Method*. The research used grounded theory (B. G. Glaser & Stauss, 1967; C. L. Glaser, 1978). The study was conducted in two hospitals in Brazil that had different policies regarding parental visits in the PICU—one was restricted, the other was unrestricted.

Data were collected using systematic observations and open interviews (24 total). Families were invited to participate in the study, and informed consent was obtained. Data were composed of demographic and relational information in the form of genograms constructed during the first interview.

A total of 24 family members from nine families participated in this study. Ages ranged from 8 to 53 years. Of the families, six consisted of two parents joined in matrimony and several children. All of the fathers held jobs outside the home, whereas six of the wives were employed outside the home. Only one of the sick children was able to participate in the study. Two grandmothers and one aunt also participated in this study because parents had introduced them as family members. The families were seen between one and four times for interviews, which were audiotaped and lasted from about 40 minutes to 1 hour. No one refused to participate or to sign the consent form.

The question that oriented the interviews was, "How has it been for you and your family to have a child in the PICU?" Family members were asked to tell their stories in a way that made sense to them; the interview was redirected to this orienting focus when necessary. New questions ensued as categories were developed during data analysis, which took place concurrently with data collection.

*Findings*. Analysis drew forth two phenomena, one of which will be described in this article: living the possibility of losing a child. This phenomenon represents families having expectations and creating strategies to try to preserve the family unit. The phenomenon contains categories of family movements or behaviors that aimed at protecting families from what was described as the "definite break," the

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her students have conducted research projects as part of their graduate and undergraduate work. The following brief report features the doctoral dissertation of Dr. Regina Szylit Bousso, now a faculty member at the Universidade de Sao Paulo. Correspondence concerning this article should be addressed to Regina Szylit Bousso, R.N., Ph.D., Universidade de São Paulo, Ave. Dr. Eneas de Carvalho Aguiar, 419, Cerqueira Cesar, São Paulo-SP, CEP: 05403-000, Brazil; e-mail:szylit@usp.br.

threat of family breakdown upon the child's death. Families lived this experience in a state of permanent expectation, despair, and pain, gathering forces and strengths and living with hope that they would be able to endure the experience. Within this phenomenon, certain themes, dimensions, or aspects arose.

## BELIEVING IN HELPING THE CHILD

Family members shared the belief that by being present in the hospital, they could help the child. Helping meant doing anything to avoid the child's death. Families believed that even if they could not do anything physically for the child, they could help emotionally and spiritually.

> We believe that by staying here, if something happens, we can help her . . . Even if we do not do anything, just being here I believe . . . She feels. . . . I think she feels that we are close.

## TRYING TO AVOID A DEFINITIVE BREAK

This aspect involved the actions of family members that were aimed at avoiding the risk of family rupture or breakdown. Family members attempted to adapt their lives to the new situation of having a child in the PICU. At the moment of crisis, what became essential for family members were the child's life and the preservation of the family unit. As a result, every other thing became a smaller detail of their lives. Whatever their priorities were before the child's hospitalization, such as jobs or taking care of the other children and the house, they became secondary.

While trying to understand what was happening or what might happen to the child, family members compared their child with the others in the PICU. The moment family members could not be inside the PICU because of regulations or even as a result of their inability to tolerate watching the child suffer, they still stayed in the hospital, remaining as close as possible to the child and trying to obtain information about what was happening. Family members stayed beside the PICU door waiting for information or expecting any opportunity to obtain news.

> We have other children, but in this situation, she is the priority . . . Besides, we also have bills to pay, we need to work, we must take care of our house.
>
> We compare because we want to know what can happen.

## LIVING UNCERTAINTIES

The phase of living uncertainties was another aspect that permeated the experience of the family because everything was uncertain for family members. They did not have an explanation of why the child needed to go through this experience. In addition, the length of hospitalization was uncertain, the child's state was unstable, and the prognosis was not clear. Living uncertainties were a part of the context, which can be described as a very painful time for the family in which they experienced ambivalence and unknowing in facing the possibility of losing the child.

> I went home concerned about him because they didn't know if they would need to intubate him . . . If he gets worse during the night, they will need to put the tube in.

## LIVING A DRAMA

Living a drama was to spend days and nights speculating indefinitely about the reason why all this was happening to them. Family members knew that making these endless inquiries was a drama, but they could not help it. There was a great deal of suffering involved when family members watched the professionals carrying out procedures and realized they could not do anything to help the child. They also suffered seeing the child intubated, observing the child's own suffering, and seeing the child being threatened with invasive and restrictive apparatuses such as tubes and respirators.

> You stay in the PICU for a while, then soon they come and start moving him from side to side and again they will try to pick another vein . . . it's too much suffering.

## LIVING AN ANGUISHING WAIT

The experience of living an anguishing wait revealed that during the process, family members experienced situations in which they could not act decisively to save the child. In the meantime, all they could do was wait. In this action of waiting, the family continued to hold the belief that at the end of the experience, the child would be with the family again. The journey from home to the hospital for visits seemed very long, permeated by despair and panic. There were fears of thinking the child could be worse and feelings of panic at not finding the child in the PICU when they returned.

> At home, I am depressed, I'm not interested in anything, I spend my time sitting around, I don't want to watch TV, I don't want anything, anything. I keep thinking if he will be alive when I arrive there the following day.

## SUFFERING SOCIAL PRESSURE

After the initial period of shock and fear, the family began to reconsider the areas of their lives that had to be put aside. Suffering social pressure revealed the pressures family members experienced because their lives had to go back to normal. This occurred when family members realized that life out of the hospital still went on and that they should resume their activities, mainly their social commitments that could not be avoided in spite of the child's hospitalization.

> My colleagues told me that there has been some pressure from my boss. This is because permission to go to the doctor was valid for only 1 day, so yesterday, I had to go back to work.

## REACHING THE LIMIT OF THEIR FORCES

Reaching the limit of their forces occurred when family members realized how much they could tolerate physically and emotionally but knew they could not give up. During the experience of the illness, they could not be positive and energetic all the time or even strong enough to carry on. Sometimes, they noticed they were at the limit of their forces and courage. Family members lived the experience, doing their best to preserve each other. They stayed in the PICU, considered all the possibilities to protect the child, and tried to be strong, but when this control escaped their hands, they appeared to need a pause or respite.

> We stay here all day long until the time that we leave the PICU . . . When we can't tolerate to see her suffering any more . . . then we leave.
>
> We don't have a fixed time to leave . . . Up to 10, 10:30 . . . 11, after, we say that we'll go home, but then we enter the ICU and stay there looking at her . . . until the time we go home.

## TRYING TO WORK WITH THE UNBEARABLE

This category represents the new strategies that family members, living with uncertainty 24 hours a day, adopted. These strategies arose from their suffering and the anguish and despair lived during this period of uncertainty and losses. They recognized that they must help each other go through the difficult moments by being together, giving support, talking, consoling, advising and hearing each other, and doing things they did not do before the illness.

Although family members may not have had a formal religion, believing in a larger force gave them strength, which helped them to recharge their forces and hopes. They held on to God, trusting that this would offer more strength and resources to survive the chaos.

> We are trying to hold on to each other. When one is down, the other one tries to cheer him up to encourage him . . . We can't all be down at the same time, otherwise we go out and kill ourselves!

## BEING HELPED

Being helped was family members' acquisition of followers, friends, or relatives who encouraged them to continue hoping for the best. Being helped was like a chain that was formed around family members to help them hope. It represented people persuading the family to feel hopeful, people who were close to, who heard, who shared the suffering, and who provided relief for the family. They were people who brought new actions and thoughts and tried to soften the suffering. As a result, the family felt stronger and more hopeful. It was additionally helpful to speak with other families who also had a child in the PICU.

> It's good when we see other people concerned about us, even the other parents that are here, when they come and they ask us about our child, we feel better with that.

## BEING STRENGTHENED

Being strengthened was the family knowing that the road was long and slow but that it could lead to a happy end. When family members perceived there were possibilities for the child's cure, they were more hopeful for the preservation of the family unit. Family members believed their family would be stronger for having had this experience. In this strengthening, family members became capable of seeing a happy future and of believing that the child would recover, but they also knew they should have patience because it could be slow and it would not be easy. They continued to believe the child would be part of the family again as before, although there may be relapses.

> We must be strong, must believe that she will get well. We have the two ideas in mind. We know that she can't resist, but we need to believe that she will.

## FEELING UNITED

Feeling united was the family members' feeling that they were closer to others. Family members described investing their forces in trying to strengthen the borders of the family unit. The family had the perception that one of the consequences of this process was its own union.

> At least it is being good to unite our family. Ouh! We are much closer now . . . The whole family is united.

### HAVING THE CHILD BACK

Having the child back was the family recovering their child to the family unit, although partially. This theme can be explained by the improvement of the child's condition, thereby forecasting discharge from the PICU. As the life-threatening illness diminished, the family became more comfortable taking care of the child and consequently stayed closer to the child.

Family members resumed interacting with the child, more confident that they could take care of the child. Family members still did not have the same power or control they had before the disease. For example, they still needed to ask for authorization to hold the child in their arms and to take care of him or her.

> Now, I am a little bit calmer. He is already more awake, sticking tongue out. . . . He's already getting as he was before! Now, he just needs to learn how to suck again.

### REASSUMING CONTROL

A new stage began from the moment family members noticed they were going to have the child back. In this phase, the family appeared to be reassuming control. This phase showed the family recovering its powers, its autonomy, and even having a larger control over the situation. Family members viewed their experience from another perspective. To have the child back made family members feel strong and allowed them to reassume control.

> Yesterday afternoon, the nurse let me give the baby bottle, later I helped her to pee. . . . We know that mother's care is different. . . . The nurses take care well, but it is not the same as the mother.

### FEELING PRIVILEGED

Feeling privileged is how family members felt about everything they experienced as they compared their situation with other families and saw other children with worse diagnoses in the PICU. Amid so much suffering and panic, they believed they offered the best to their child and they felt lucky. They saw the world around them and realized their advantage over the others, having been saved from a great suffering.

> Although we had luck, they extubated him and he feels fine, but we know that some children don't feel well.

## HAVING A DEFINITIVE BREAK

The family did not always have the chance to have the child back. Some families endured a different end result, expressed in having a definitive break. Having a definitive break occurred when the child died. The family was faced with the finality of the child's death and the end of hope. This occurred when the family was informed that the child had died or when they became aware of the imminence of the child's death in spite of all the efforts.

> I only realized when the nurse left the PICU and informed us. . . . I was outside waiting. I couldn't stand being with her until the end, . . . She died and at that time, hope ended. . . . When she died, I noticed that I couldn't hope anymore, I couldn't breathe for her, and I knew her lung couldn't work anymore. . . . I didn't have anything else to do.

## NOTICING THE EFFORT NOT BEING REWARDED

The families who lost their child realized they had bad luck. Noticing that their efforts were not rewarded is the first explanation they gave for the drastic impact of the child's death. They recognized that all the activities they had employed as well as the efforts of the professionals who participated in the process were not enough.

> Unhappily, we didn't have the same luck of other families; we realize that all the effort was not rewarded.

## REFERENCES

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory.* New York: Aldine.
Glaser, C. L. (1978). *Theoritical sensitivity* (2nd ed.). New York: Gardner.

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