The Emotional Reactions of Parents to Their Premature Baby

Author: Hynan, Michael T, PhD

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Full Text: Headnote ABSTRACT: Parents have a confusing variety of emotional reactions to the stress of a high-risk birth. Terror, grief, impotence, and anger are common feelings for these parents. Some of these reactions bring families closer together; at other times these emotions pull spouses apart. It is essential to recognize that even though these emotions are very troubling, they are normal experiences during a life-and-death crisis. Instead of attempting to escape these feelings, the parents' recovery from the stress of a high-risk birth is dependent upon how well they accept their feelings and the changes in their lives. When my son was born 10 weeks prematurely in 1980 and was hospitalized for 7 weeks, I found no books or journal articles that would help parents struggle with this emotional crisis. Being a clinical psychologist, it was very important to me to understand the emotional hurricane I was experiencing. How could I help myself, my family? I didn't do very well at understanding then. If what you are feeling is a confusing mixture of terror, grief, impotence, anger, and whatever else; you are fortunate if you can understand tap water. Being a psychologist did not make high-risk parenting easy for me, although I think it did help me in some small ways. It was not until most of the crises were over that my understanding of my emotional reactions began to fall into place. Hindsight, obsessive thought, compulsive reading, and talking with many high-risk parents have clarified a few things for me. The experience redirected much of my academic work into writing (Hynan, 1987, 1988, 1991) and giving talks about the emotional reactions of high-risk parents. This article contains some of my recent formulations. I hope that when veteran parents and peri-natal professionals better understand the emotional upheaval of a high-risk birth, then future parents can receive meaningful support during their ordeal. The emotions of terror, grief, impotence, and anger are common in high-risk parents. I will describe examples of their occurrence. I will also make one point repeatedly in this article. During a high-risk birth the crazy, mixed-up feelings of parents are a natural and normal reaction to incredible stress. When I talk to groups of high-risk parents, I feel like I am addressing a meeting of the veterans of the baby wars. If you have been in the life and death battlefield of a neonatal intensive care unit (NICU), you are going to be disorganized and upset for months-some of us for years. We feel crazy, and we want to return to normal quickly. But that is the worst thing we can try to do, because we can't stop or reverse the natural healing process of our emotional reactions without doing damage to ourselves. The only things that are normal for high-risk parents are terror, grief, impotence, and anger (plus assorted other feelings like guilt, frustration, jealousy, and intense fatigue). The birth of a high-risk baby changes family members forever (Featherstone, 1980; Harrison &Kositski, 1990; Nance, 1982). I believe that the best a high-risk family can do is to struggle to change and adapt together. Unfortunately, the stronger temptation is to grow weary of the long hardships, such as no sleep and extended hospitalizations, and wish that we could return to the way we were. But the process of emotional recovery from a high-risk birth is long and hard. A family is more likely to change in harmony and come through the crisis together if they let themselves be changed, rather than try to deny what is happening. TERROR On July 18, 1980 my wife Lauren and I were finishing our first European vacation in a rural town in the northern Netherlands. Her pregnancy was going beautifully, and we were having a wonderful time. Ten days later we were the terrified parents of 2 lb., 10 oz., 30 week gestational age, Baby Boy Hynan (his official name for the first three days of his life). Thank God we were back in Milwaukee. This turn of events was never even a fleeting bad dream in our expectations of the birth of our first child. Both my wife and my son were in life-threatening situations; we felt overwhelmed with the stress we were feeling. But we also realized much later that, in a strange way, the worst times of a crisis are also the easiest

times for a high-risk family. Terror is the easiest emotion to cope with when the danger is at its worst. It seems contradictory to consider that the worst of a crisis is also the easiest time, so I will explain. Hans Selye (1956), has written about the stages of a crisis reaction. The first stage is the Alarm stage. This stage is when the danger is at its maximum, and we feel like we are facing a loaded gun. In the Alarm stage people generally pull together to fight the common foe. Everyone's attention is focused on coping with the danger facing us. We don't have the time to figure out the best way to cope, or to worry about how well we are doing. We just do it, and husbands and wives tend to do it together. Five days before my son was born, I woke up at 2:00 a.m. when my wife called out to me from the bathroom. When I got there, I found her sitting in the bathtub next to a very large clot of blood. That Was our Alarm stage. It was very clear then that there were only three things to do. Call the doctor, get dressed, and get to the hospital. We were terrified, but it was a simple situation to cope with because so much was out of our control. And we were together in coping. So, paradoxically, the Alarm stage is easy because we expect ourselves to be upset. We know that it is all right to be very afraid, because we are facing possible death. High-risk parents find that coping later on, when the danger has decreased, is more difficult. This is because we expect ourselves to be feeling better, to be more in control, when our babies seem to be out of danger. This is seldom the case, however, because our emotional recovery only begins when our baby's physical health has improved. At that time high-risk parents are more likely to doubt their sanity and find the most difficulty in coping. Terror lessens a bit when the danger starts to decrease. At this time parents begin to cope with grief. GRIEF First, parents grieve over the loss of their dreams of childbirth. Lauren and I were supposed to be in a recovery room, together, holding hands with a pink, 7 pound baby snuggling by her breasts. We were supposed to be exhausted, but in ecstasy, after a natural childbirth. I did not want to perform my first baptism that day. Instead, we got an emergency C-section. Lauren had been unconscious, and I wasn't there. Lauren was just recovering consciousness when the transport team wheeled our son's isolette into her room for a brief look. Lauren had to stop vomiting when she turned and tried to focus. Her first words to her son were, "It's hard to believe anything good could come of this." Those were not the words of an ecstatic mother. This was not our dream. Instead, we were left with those intense, terrible images that come back to haunt high-risk parents years later. This grief is difficult, but necessary. The pleasant dreams of childbirth must be laid to rest, if high-risk parents are to begin relating to the baby they do have. The second part of grief is anticipatory grief, which occurs when parents prepare themselves emotionally for the possibility of their baby's death (Cramer, 1976; Parkes, 1972). To avoid being overcome by this terrible fear of death, anticipatory grief helps parents to prepare for the worst possibilities. Anticipatory grief is a natural reaction, and it has some benefits. It insulates the vulnerable high-risk parent from even greater pain. One example of anticipatory grief is the fact that some parents of premature babies delay naming their baby after birth. These parents feel that it would be easier to face their baby's death, if they gave it no name. Even though I baptized our son, "Christopher," in the first hour of his life; I avoided giving him an official name for 3 days. I also avoided telling anyone other than close relatives and friends that Lauren had given birth until Christopher had survived for 4 days. I had decided that, in case of death, I would tell acquaintances that Lauren had miscarried. It would have been much harder for me to say that we had a baby who lived for a day and then died. This lie was the result of anticipatory grief. I was trying to keep my sadness from overwhelming me. Anticipatory grief is difficult to manage because it forms a temporary barrier against the deepening of bonding between parents and their sick baby. When we prepare for death we insulate our feelings. The more we love our baby, the worse we would feel if he or she dies. So anticipatory grief both helps parents and causes confusion. When our babies have survived for a few days, we may wonder why we don't feel more attached to them. We may think we are terrible parents because we don't love them more. This can be confusing and upsetting, but it helps to realize that anticipatory grief is a normal process. The job of parents at this stage is to slowly begin to take the additional risks of deepening their attachments with their baby. Grief is also difficult because husbands and wives often cope with it at different times. I believe that the grief process takes much longer for mothers, who have usually formed more of a bond

with the baby in their womb. I also believe that mothers have sharper images and stronger expectations for the dream of a perfect birth. So mothers and fathers are often out of synchrony in coping with grief. Lauren and I were. Four days after Chris was born, I had already spent many hours with him. Lauren was 10 miles away in another hospital. I remember eagerly describing him and showing her his Polaroid picture. I could not understand then why Lauren could only look at his picture for a few seconds, before putting it in a drawer. The differences in our feelings then were difficult for me to understand. Now the reasons are very obvious. But those differences point out that coping for a couple becomes more difficult as the danger decreases, because husbands and wives may be on different wavelengths. When the medical problems are getting better parents enter the second stage of stress reactions, the Resistance stage (Selye, 1956). In the Resistance stage danger is still present, but it is not immediate danger. Our energy and defenses are still directed towards resolving the crises, but it seems that our lives may be coming back under our control. Even though things objectively seem to be getting better, this time brings even more difficulties for high-risk parents. Lauren and I found ourselves in the Resistance stage about two weeks after Chris was born. Lauren had been home for a week, and her blood pressure was finally under control. Christopher was breathing room air, taking breast milk by gavage, and gaining weight. It seemed like the time to lean back, take a big sigh of relief, and say, "It's over; we made it." What an illusion that sense of stability was! It was an illusion because we were still reverberating emotionally from the biggest shock of our lives. We believed that we could control our feelings and lives now, and return to stability. But our feelings wouldn't let themselves be controlled the way we wanted. This is the time for impotence, the most dreadful of the emotions of high-risk parents. IMPOTENCE The feelings of impotence come when parents find that they have no power over their lives. There are four types of impotence for high-risk parents: depression, frustration, sexual impotence, and jealousy. Depression Two weeks after Chris was born, Lauren became very depressed. Lauren and I can sit back now and realize that there were many good reasons for her depression. She had lost the cherished vision of a natural childbirth. She was recovering from surgery. She had been afraid she was never going to awake from the anesthesia. Her baby was going to be in the hospital for at least another month. It was obvious that Lauren's depression was a very normal reaction to what had happened. This was uncomfortable enough, but what made things worse was that Lauren thought she shouldn't be depressed. On the surface our lives were getting better; but Lauren had to conserve all her energy just to express milk, travel the 50 miles to the hospital to see Chris, and get out of bed to eat dinner. Even this was more than she could do. Washing her hair one morning took so much of her small reserve of energy that she had to spend the rest of the day in bed. Lauren didn't want to feel like this so she made the common mistake of saying to herself, "I shouldn't be depressed. I'm going to stop feeling depressed." Then Lauren began to fight her depression, and she lost. Her depression was a normal reaction in the first place, and its expression would not be denied. When Lauren found out that she could not control her depression, she became even more depressed that she was not in control of herself. Then it was back to bed. This was one of the few times that my training as a clinical psychologist helped our adjustment. I had my own feelings of depression at this time, and Lauren's depression depressed me even more. As a husband I was tempted to say, "Don't be depressed. There's nothing to be depressed about now." The psychologist in me made me realize that saying that would have been just as incorrect and stupid as saying, "Stop bleeding" when I saw Lauren in the bathtub three weeks earlier. So I was able to help Lauren see that she was not going crazy, that her depression was normal, and that it would go away more rapidly once she had accepted it and worked through it. In this Resistance stage there is the strong temptation to return to the comfort of having your family be the way it used to be. Things look like they may work out all right, and parents want to feel better quickly. But even though the pressure of a life and death situation is diminished, the emotional reactions remain. All family members have strong feelings about a high-risk birth, whether the feelings are expressed or hidden. There is going to be family instability. High-risk parents should expect conflicts. The greatest danger lies in believing that there should be no conflicts and that these unpleasant emotions are signs that we are inadequate people. If we believe that we

should be getting over this trauma quickly, and then bang our heads against the wall trying to control the uncontrollable, we are only asking for more trouble. Let me give you another example of this dilemma. After Chris came home, he had no major medical problems. It was apparent after a couple months that he was doing fine. But I was still afraid. I was exhausted from doing 4 a.m. feedings and waking up when Lauren did the midnight feeding. Even so, I woke up repeatedly wondering if Chris was alive. I heard him cry even when he wasn't crying, and laid awake trying to tell the difference between his crying and my hallucinating that he was crying. My initial reaction was, "This is crazy, I don't need to be this afraid." And the more I tried not to be afraid, the more fear I felt because I could not control myself. As I tried to figure things out, I just made myself worse. The solution was to accept the fact that I was afraid. (Although this solution was simple, the process of acceptance is often slow and anxiety-provoking.) This was not the most pleasant discovery, but it was the least painful. I finally learned to say to myself, "OK, Michael, you are afraid for Christopher's life, and you will go on feeling that way, maybe forever." Once I learned to accept my fear I slept better. I still woke thinking Chris cried, but I could go back to sleep without berating myself for having woken up in the first place. Frustration Extreme frustration is the second aspect of impotence. There is one word parents use most often to describe their feelings while their baby is in an NICU. That word is roller-coaster. A few grams of weight can turn despair to hope, and vice versa. But parents have little control over what happens to their baby, and what little parents can do is clearly not enough. The only thing Lauren could uniquely do as a mother was produce breast milk. Lauren expressed so much she produced blisters on her fingers, and not much milk. Recall the phrase, "Don't cry over spilled milk." After Lauren had expressed for what seemed like the hundredth time, we did cry when the bag slipped and that precious ounce and a half of milk hit the floor. Talk about extreme frustration. Crying was the only normal thing to do (other than breaking a window or throwing a chair). High-risk parents are strapped into the roller coaster with little control over its movement. When parents begin to accept the fact that much is out of their control, the frustrations begin to decrease. Lauren and I were lucky to find a way to help each other during our times of frustration and exasperation. We developed a catch phrase to let each other know that we had survived this far, and we would probably be alive tomorrow. Lauren would look at me (or I would look at her) and say, "All it is, is hard. All this is, is hard." Saying this helped us realize that we had come through some rough times, and we could cope with this frustration, too. Sexual Impotence The third type of impotence is the sexual kind. One of the very hard things about coping with a high-risk birth is watching one's love life disappear. It is well known that any normal, full-term birth will disrupt loving sexual relationships. I believe that it is important to acknowledge that high-risk births cause even greater sexual problems (Fischman, Rankin, Soeken, &Lenz, 1986), especially for couples for whom sex is the primary way of expressing love. I would hope that both peri-natal professionals and members of parent groups openly discuss the fact that sexual disharmony is a common reaction to a high-risk birth. If this is acknowledged, parents can begin to accept this disruption of their lives. This acknowledgement can remove the pressure for having sex, and allow parents to rediscover their own sexuality when the time comes. I have talked with high-risk parents whose sexual relationships have been disrupted for years. This is not difficult to understand. If you know that you almost died from childbirth, or if you spend months listening for alarms from an apnea monitor; you are not going to feel very sexy. But it can get worse. If your partner does feel sexy and pushes you for a little of the old romance, you're probably going to freeze and resist the pressure. Then a problem that ordinarily takes only months to resolve may become a constant problem. Nothing is guaranteed to work perfectly, but open communication and agreeing to take the pressure off having intercourse have been helpful. Parents have told me that if they stopped expecting themselves to be the lovers they were before, they were surprised to find their sexual interest returning. JEALOUSY Jealousy is another normal feeling for high-risk parents. An incubator that is foreign to me separates me from my baby. When I do touch my baby, I feel clumsy. Most of the time my baby gets attention from others, whose movements are smooth and assured. I'm only around my baby for a few hours a day. How will my baby know me as its father? How can I compete with nurses and doctors? Jealousy is feeling impotent

about being a parent, and envying others who are doing a better job of baby care. There are two things which can help jealousy. First, mothers can be told about research that has shown that babies learn to recognize their mother's voices while they are still in the womb (DeCasper &Fifer, 1980). So a premature baby can identify its mother and can tell her apart from others. Realizing this can be reassuring. Second, parents can realize that they can be the only ones in their baby's life who do not cause pain. We know that the lives of high-risk babies are filled with pain. Babies have many aversive encounters with doctors and nurses each day. But parents don't draw blood or put in IVs. Parents can learn to match a soothing voice with a touch that is always gentle. Their baby will then learn that its parents are "the good guys." ANGER Any psychology major should be able to predict that high-risk parents will become angry during their baby's hospital stay. Most theories of aggression cite pain and frustration as major causes of anger (Berkowitz, 1983; Zillman, 1979). Not only are these parents going to be angry, some are walking time bombs. Peri-natal professionals, when speaking candidly, will admit that during an extended hospitalization some member of the medical staff is bound to make a mistake in any baby's care. It may be a frightening mistake, or something that is trivial, but a mistake will occur. And the frustration tolerance of high-risk parents is very low. It is not difficult for the medical staff to identify those few, seething parents in the NICU, just looking for someone to do something wrong so they can get mad and let everyone know about it. Such angry parents are very troublesome to well-intentioned doctors and nurses, who wonder, "Why do they do this?". The answer is easy to understand. When the parents have discovered the evil deed and loudly let everyone know about it, they can feel in control and potent for a short time. What a great vacation from impotence! Most parents I have talked to have told me that, at some point during a hospitalization, someone on the medical staff has either withheld information, misled them, or lied to them about something. Whether this is actually true is not important to me. Reality is less important than recognizing how parents feel and realizing that they will be upset. Sensitive members of the medical staff recognize this and have become skilled at understanding and coping with the anger of parents. It is crucial for professionals to be able to do this. There are times for high-risk parents when feeling understood by the medical staff is more important than the quality of care given to their baby. After the passage of months or years, most high-risk parents recognize that their crises are slowly being resolved. (There is no state of resolution, only a continuing process.) What these realizations mean is that their family has been going through a necessary course of adjusting to their tragedy, by accepting their changed lives and their baby. The dream of a perfect birth is gone, but that is all right now. Parents, even if they have a child with multiple handicaps, begin to experience the pleasure of their new love. In feeling this love, parents recognize that at least parts of life, again, are good. All it is, is hard. SUMMARY A high-risk birth is a painful crisis which affects a family forever. As human beings we try to minimize emotional turmoil and return to the mythical peace of stability. But the crisis must run its emotional course. It is normal for parents to feel terror, grief, impotence, anger, and other emotions in disturbing combinations. These emotions are signs that parents are coping well with the crisis, not doing poorly. Parents can cope better by accepting that these are very hard times to be endured, and by seeking and accepting emotional support. Perinatal professionals and members of parent groups can provide the most useful support by acknowledging parents' feelings. To paraphrase part of a Billy Joel (1976) song,. . . just surviving is a noble plight. References REFERENCES Berkowitz, L. (1983) Aversively stimulated aggression. American Psychologist 38, 1135-1144. Cramer, B. (1976). A mother's reaction to the birth of a premature baby. In M. Klaus and J. Kennell (eds.), Maternal-infant bonding (pp. 156-166). St. Louis: C.V. Mosby. DeCasper, A. &Fifer, W. (1980). Of human bondage: Newborns prefer their mothers' voices. Science 208, 1174-1176. Featherstone, H. (1980). A difference in the family: Living with a disabled child. New York: Penguin Books. Fischman, S., Rankin. E., Soeken, K. &Lenz, E. (1986). Changes in sexual relationships in postpartum couples. 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