When parents learn of the heart defect, they are initially in a period of shock followed by high anxiety and fear that the child will die. The family needs time to grieve before they can assimilate the meaning of the defect. Unfortunately, the demands for medical treatment may not allow this, instead necessitating that the parents immediately give informed consent for diagnostic-therapeutic procedures. The nurse can be instrumental in supporting parents in their loss, assessing their level of understanding, supplying information as needed, and helping other members of the health care team understand the parents' reactions (see Family-Centered Care box).

## Family-Centered Care

## **Diagnosis of Heart Disease**

Remember, we don't have your experience. We don't see children every day who have heart disease. We would have been upset finding out our child had to have his tonsils out. How could we ever be prepared for this? Please remember, we only know people who have trivial heart murmurs. How could we ever expect this to happen? And to us, this is the worst problem we've ever heard of.

We still fear most what we don't know and understand. Be honest with us. If you don't know either, tell us. But at least don't leave us wondering about what you know and we don't. Not knowing anything really can be worse than knowing something bad. Be honest but don't strip us of hope.

Please, remember we are trying to learn complex information in a moment of time. And trying to learn it in a context of great pain and emotional investment. This is our lives you're talking about. Please be thorough but keep it simple. Tell us again, maybe even again and again, when we can hear better.

From Schrey C, Schrey M: A parent's perspective: our needs and our message, *Crit Care Nurs Clin North Am* 6(1):113–119, 1994.

Severely ill newborns usually remain in the hospital. Parent-infant attachment is supported by encouraging parents to hold, touch, and look at their child and providing time and privacy for the parents to spend with their newborn. (See Chapter 8 for