

Critically Ill Newborns Require Special Treatment

by Herman A. Hein, MD

I would like to share some thoughts with you about a group of youngsters who are ventilator dependent. These are infants with chronic lung disease. By and large when you hear neonatologists talking about chronic lung disease, we are talking about bronchopulmonary dysplasia (BPD). We believe this is a laterogenic disease that results from the use of high concentrations of oxygen and from trauma to the lungs caused by ventilation. Regardless of the causes, these babies are our version of ventilator-dependent patients.

I'd like to share with you the problems these babies create for us in neonatal intensive care, some of the problems I think we create for them. Then I would like to share a possible solution to some of these problems.

In November, there were eight infants less than 12 months old receiving care in Iowa hospitals because they were ventilator dependent. Seven were housed at University Hospitals in Iowa City, and three others had just died within the past several weeks. Presently there are no Iowa infants receiving home ventilator care. There are some older children on ventilators, but not a large number, probably somewhere in the range of four to 10 in the entire state. There are six infants with chronic lung disease that are home and require supplemental oxygen and

another two that are housed at University Hospitals. To the best of my knowledge there are no Iowa infants receiving care in chronic care facilities because they are ventilator or oxygen dependent.

The number of beds available to provide care for critically ill newborns is a chronic problem in most neonatal intensive care units. I am not prepared to discuss why neonatal intensive care units have not expanded their capabilities to meet this need, but I must note that financial matters, including the availability of nursing personnel, are important issues. Contrary to popular opinion, which is consistent with the hue and cry over rising costs of medical care, many hospitals are not financially solvent. A large number of hospitals that provide tertiary neonatal intensive care are teaching institutions, and these institutions are experiencing severe financial constraints. Accordingly, the hope for expanding facilities by these institutions is not a reality in the near future.

In the meantime, babies with chronic lung disease are occupying beds two, four or six months in the neonatal intensive care units. Eventually the chronically ill ventilator-dependent infant is moved to another area of the hospital, usually to a pediatric intensive care unit or to an intermediate type of unit on a pediatric ward. The

move is not based on the baby's or the infant's needs, but rather on the availability of a bed. The net effect of this type of uncontrolled transfer is fragmentation of care.

Related to this matter is the general issue of primary care givers for these infants. Most people would agree that as things evolve, the neonatologists are the ones who are and should be responsible for these babies. But once the baby leaves the NICU, this really isn't true in many instances. Because of the heavy workload of most neonatologists, the logistical type of problem is a major one in trying to give care when the babies are scattered throughout the hospital. For example, in our hospital, once a baby leaves the NICU and goes to the pediatric ICU, it's a three-block walk. If the baby goes over to the intermediate level on one of our pediatric wards, it adds another two blocks. Logistically it gets to be a major problem, resulting in fragmentary care. In my experience there really hasn't been another group of physicians that has leaped forward and said, "I'm sure willing and eager to take care of these kiddies with chronic lung disease." I guess I thought that pediatric pulmonologists would be first in line, but again, in our institution that simply has not been the case. They are willing to consult if requested, but they are not available to take over the primary care.

The problems that infants with chronic lung disease present are complex and varied — respiratory, cardiovascular, nutritional, growth and development, surgical and many, many more. If we are going to be able to provide home care for ventilator-dependent infants, it is important that coordination of hospital and community resources begin some considerable time before this move is anticipated. Given the current state of affairs, I am not very optimistic that this is going to occur with any regularity. To help solve the problems, I believe there are several things we can do.

Facilities should be developed within acute care institutions that provide neonatal intensive care to

house all ventilator-dependent infants who are six weeks of age or older and are making no progress in being weaned from the ventilator. Medical supervision should be provided by a neonatologist or a pediatric pulmonologist, and appropriate consultation can be requested as needed. I would also suggest that a cadre of nurses provide care to the children in this special unit. Using this approach, the following advantages emerge: 1) location of care giving ceases to be a problem; 2) there is continuity of care; 3) coordination with community resources can be anticipated and begun with sufficient lead time; 4) knowledge will accumulate because of the consistency of care given by nurses as

well as physicians and other providers; and 5) practical, problem-oriented clinical research can be fostered.

I believe it's important for us to begin to accumulate a solid basis of knowledge about this vexing problem, including not only aspects of prevention but also those measures that are related to chronic care giving. This information should be refined and disseminated nationwide as soon as possible. Perhaps if major teaching institutions can combine this group of infants in one clinical area and carefully document the results of care giving, we can begin to make progress in what currently is a frustrating experience for parents and caregivers alike. ●