

## A Program for Improving the Psychosocial Outcome of Infants with Bronchopulmonary Dysplasia (BPD)

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**Abstract:** None available.

**Full Text:** INTRODUCTION Bronchopulmonary Dysplasia (BPD) is a chronic lung disease of premature infants who are given oxygen via a ventilator for treatment of respiratory distress. Increasing numbers of surviving infants with BPD strain the capacity of the health care system to provide for their needs and those of their families. Improvements in antenatal and postnatal care, as well as the development of highly effective technological equipment, result in the survival of smaller and younger premature infants who are susceptible to developing this condition. In 1984, approximately 240,000 infants were born with a birthweight of under 2500 grams. Nine thousandthree hundred of the survivors developed BPD (see Table 1).<sup>1</sup> Of the infants whose birthweights were under 1500 grams, Avery and colleagues found that about four percent still required supplemental oxygen at three months of age.<sup>2</sup> Many of these infants spend the first three to six months of life in a hospital setting and many are discharged with sophisticated life-supporting equipment such as tracheostomy tubes, oxygen tanks, suction apparatus, and respiratory monitors. While these infants are in the hospital, they develop an aversive personality characterized by social withdrawal, inability to form attachments to a primary caregiver, and inappropriate self-stimulatory behaviors. Activities involving the oral cavity, such as sucking and swallowing, become distasteful and unpleasant to these infants, and this leads to prolonged delay of normal feeding behaviors. These infants have plastic feeding catheters inserted through their noses on a long term basis, and often require the additional placement of nasal prongs to deliver oxygen.

**Table 1**

<i>Birthweight (grams)</i>	<i>US Births (1984)</i>	<i>US Neonatal Mortality (1980)</i>	<i>Neonatal Survivors</i>	<i>Percent Survivors with BPD</i>	<i>Total Infants with BPD Per Year</i>
500-1,500g	39,045	43.1%	22,217	33%	7,332
1,501-2,500g	202,606	2.4%	197,743	1%	<u>1,997</u> 9,309

The extra months that these BPD infants spend in intensive care creates the potential for severe emotional, social and developmental delays. Studies have shown that these infants may significantly benefit from individualized behavioral and environmental care in the neonatal intensive care unit. A controlled investigation by Als and colleagues compared two groups of nursing care procedures for the very low birthweight premature infant at risk for developing BPD.<sup>3</sup> One group received carefully controlled sensory input to minimally disrupt the infant's homeostasis. The three major areas of caregiving that were addressed included 1. the physical environment of the infant, 2. the direct care given to the infant, and 3. discharge planning. In the experimental group, the researchers found that these babies showed significantly briefer stays on the respirator, that their feeding behaviors normalized earlier, and that they showed significantly better behavioral regulation at one month of age adjusted for degree of prematurity, and significantly better Mental and Psychomotor Developmental Indices at three, six and nine months post estimated date of conception as measured with the Bay ley Scales of Infant Development. The stability of coping behavior may be established by six months of age. If this is true, the interaction between the infant and early caretakers may define the future behaviors and

possibly the developmental outcome. The milieu of the neonatal intensive care unit is not conducive to the development of self-regulatory behaviors for the infant, nor is it supportive of parental attempts to successfully form attachments with their infant. In the early lifesaving phase of treatment, repeated painful procedures such as intubation and blood drawing are required on a frequent basis. Endotracheal tubes and oxygen lines inhibit neck and body movements, limiting the development of normal movement patterns. Sleep cycles are disrupted by continuous light, and the constant din of medical personnel engaging in their daily activities does not allow for a daily period of peace and quiet. These infants do not respond in any observable way to their parents' concern and bedside attention. Their poor muscle tone, lack of movement and weak reflexes are often interpreted as a disinterest in the environment. The baby is regarded as a "technological miracle," not a human being. These behaviors intensify parental feelings of anxiety, guilt and disappointment. Unfortunately, the hospital staff also finds it difficult to form a positive supporting attachment with these infants. Successful development of family connection with the infant is therefore just as important a goal of successfully managing BPD as is optimal outcome in terms of pulmonary function or neurological development.

#### MODEL OF CARE

The staff at a tertiary care hospital and a pediatric rehabilitation hospital recognized the deficiencies of the total care of these infants and their families. In October 1984, they united to develop a multilevel, multidisciplinary model of care with the support of a demonstration grant from the Maternal and Child Health division of the United States Public Health Service. This model is based on a belief that all infants would benefit from early discharge to home. In the home, the family interaction improves chances for a more normal outcome socially, emotionally, and developmentally. It is also cost-effective in terms of days spent in the expensive hospital setting. Service delivery is planned and integrated throughout three levels. These include a tertiary care hospital's neonatal intensive care unit, a pediatric rehabilitation hospital with a full range of developmentally based therapies and therapeutic activity services, and community based services which are supervised by a nurse project coordinator and include a Special Babies Follow-Up Program for BPD infants. These levels of care are staffed with medical personnel with experience in chronic pediatric illness and who function well within the concept of a multidisciplinary team. A special BPD unit for infants was developed by nurses with support of physicians at the tertiary care facility within the physical space of the neonatal intensive care unit. Protocols and treatment regimens were developed to foster a favorable outcome by reducing the number of invasive procedures and clustering treatment times. By doing so, the infants spent more time in physiologic sleep cycles and the number of frequent random therapeutic interventions were decreased. A BPD weaning menu was developed which provided guidelines for gradually withdrawing ventilatory support and oxygen. It is based on a daily assessment of the infant's energy balance. In essence, the weaning menu is an exchange system for all the possible ventilatory and energy manipulations such as feeding, thermal regulation, and medical procedures which the infant must undergo to pass from extreme prematurity to a state in which he or she can enter the home. The weaning menu provides a step-wise reduction in supports that are given to the infants by medical technology and a step-wise increase in the energy that the infant has to supply to provide his/her own physiological needs. The use of daily capillary blood gas measurements, noninvasive oxygen saturation measurements, observed activity levels, and weight change are the major criteria for changes in ventilatory support. These play an integral role in determining the infant's present energy state and indicate the infant's ability to be advanced to another energy level. By using these parameters, a more controlled, less noxious method for weaning the infant from ventilator and oxygen is possible. If weaning is too slow, then hospitalization is prolonged and self-stimulatory behaviors will develop regardless of the supplemental enrichment of the infant's environment. If weaning is too rapid, then the baby will become hypoxic, leading to a state of chronic anxiety. These BPD infants are therefore at risk for developing anxiety related symptoms due to overzealous weaning from oxygen. Excessive hypoxia leads to depressed levels of awareness and significantly affects the infant's interaction with his/her surroundings. Often these signs are misinterpreted as an acute medical complication such as pneumonia or sepsis, and further unpleasant unnecessary diagnostic manipulations

occur. When extubated and stable, these infants are transferred to the intermediate care facility, where each infant and family receives services designed to promote an optimal social, emotional and developmental outcome. All infants admitted to the BPD unit of this facility are evaluated and followed daily by physical, occupational, speech and play therapists. At this level nonmedical intervention assumes a major role, since the focus is on all aspects of the infant's outcome, not just the medical status. The developmental play therapist, in addition to providing direct interventions and normalizing adaptations within the medically restrictive environment, serves as a role model support for parents throughout this hospitalization. Essential to the family's success in bringing a BPD infant home is the child's ability to respond positively to parental behavior. Bonding consequently becomes a primary concern during the play experience at the intermediate care hospital. Initially the play therapist assesses the child's skills and uses this information to structure age-appropriate play sessions. Therapists are trained regarding the need for medical precautions. They are allowed to remove the child from respiratory monitors and arrange for a portable oxygen supply during treatment sessions. This allows them to interact with the child in a less restrictive environment and may include outdoor sessions, during which the young child may first experience wind, grass, and sunlight. The play sessions are structured to facilitate exploration, mastery, and mobility through a staged and reinforced program of cues and positive reinforcement. The infant is engaged under pleasurable circumstances with a high degree of intensity, so that protective barriers that the child has erected to protect himself/herself from the noxious effects of overstimulation are overcome. The therapist works with the primary nurse, but keeps herself/himself separated from unpleasant medical experiences, so she/he may be the only individual who the infant does not associate with physical discomfort. As the relationship develops between the child and the play therapist, she/he will begin to include the parents in sessions with the child, training them in developmental play techniques, and showing them how to identify the subtle cues of the infant's responsiveness. In cooperation with the social worker, a play regimen to be used at home is developed and presented to the parents in preparation for discharge. The infant's developmental needs are addressed individually by speech, occupational and physical therapy. A similar program of interaction, goal setting and parental involvement is followed by these specialists in their areas of expertise. Feeding behaviors are addressed by weekly evaluations and recommendations are developed by the feeding team, which includes a pediatrician, speech therapist, nutritionist, and psychologist. Careful attention is paid to the infant's energy balance and pulmonary reserve. Daily weights are closely watched, and daily oxygen saturation measurements are obtained. Both weight gain and linear growth are considered to be important indicators of the success of the feeding program. The quality of oro-motor activity, in addition to the total amount consumed, is monitored by speech therapy. Poorly coordinated, forced feeding, which may lead to aspiration and choking, is not accepted, and these infants are often maintained on nasogastric tube feedings while the development of normal feeding patterns is encouraged through intensive daily speech therapy sessions.

**DISCUSSION** In the first 18 months of operation of the multilevel model of care for the BPD infant, we have demonstrated a decrease in the length of stay required for the infant with severe BPD. The medical stability was improved as seen by the documented decrease in emergency transfers (see Table 2). In addition, the number of medications these infants required when discharged was decreased. An intensive training program which included a BPD training booklet was provided at the intermediate care facility by the nursing staff. We found that many parents are eager and able to manage oxygen therapy at home. In addition, management of medications, tracheostomy tube care, chest physiotherapy and suctioning, and cardiopulmonary resuscitation were taught.

**SUMMARY** The infant with severe BPD requires ongoing medical surveillance and seems to benefit from a coordinated multidisciplinary approach to BPD in which considerations are taken for maintaining optimal oxygenation and positive energy balance early in the recovery phase. In addition, parental involvement in an intensive teaching program which includes home passes from an intermediate level pediatric hospital leads to increased parental skill and confidence in caring for these infants.

**Table 2**

	<i>1983-1985</i>	<i>1985-1986</i>
Average Age at Transfer to ICH* (Days)	139	111
Average Total Days at ICH	<u>154</u>	<u>41</u>
Average Length of Hospitalization (Days)	293	152

\*ICH = Intermediate Care Hospital

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