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Evaluation of an Education Program for Caregivers of Infants Discharged Home on Supplemental Oxygen

by

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled, "Evaluation of an Education Program for Caregivers of Infants Discharged Home on Supplemental Oxygen" submitted by Krista Anne Brown in partial fulfillment of the requirements for the degree of Master of Science.

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ABSTRACT

This study was designed to evaluate the impact of an education program on caregiver knowledge. The target group was caregivers of infants discharged home on supplemental oxygen. An education program was developed utilizing principles of adult learning and based upon specific caregiver needs identified in the literature.

A one group pre-test/post-test study design was used. The study sample was comprised of a total cohort of 18 caregivers of infants discharged home from Foothills Hospital Neonatal Intensive Care Unit on supplemental oxygen between May 1988 and May 1989. The group included both mothers (nine) and fathers (eight), and in one instance a grandmother as a primary caregiver.

The evaluation of knowledge tools used to collect data were developed for this study. Prior to study use the tools were pilot tested and reliability and validity were established. During the study a pre-test (evaluation of knowledge tool) was administered, the education program was presented and then a post-test (evaluation of knowledge tool) and program evaluation check list were given. Four to six weeks post-discharge a delayed post-test (evaluation of knowledge tool) was administered.

Infant and caregiver characteristics and evaluation of knowledge (pre-, post- and delayed post-test) scores were then summarized and intertest differences were analyzed using t-tests. Further analysis included correlation and regression to assess for relationships between the descriptive factors measured and the test scores.

Data analysis indicated that the education program significantly increased the post-test scores versus the pre-test scores, indicating an increase in caregiver knowledge. In the area of cardiopulmonary resuscitation, including the care of a choking infant, test item scores were low suggesting that this component of caregiver education was inadequate. Parents also indicated a preference for one-to-one teaching ("hands-on") as opposed to a written booklet or a videotape which were also program components.

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Table of Contents

List of Tables

Page

Table

CHAPTER 1

Introduction

There has recently been great emphasis on early discharge from hospitals (Abman, Accurso, & Koops, 1984; Daily, 1987; Groeneveld, 1986; Philip, 1975). This has included high risk infants who have been hospitalized from birth. High risk infants include the group of infants born prematurely (less than 37 weeks gestation [Korones, 1986]). Due to their prematurity these infants have an increased risk of developing chronic lung disease of infancy (bronchopulmonary dysplasia), as well as other complications related to prematurity (Arenson, 1988; Daily, 1987). As a result, many require extended periods of hospitalization in order to grow and become independent of all supportive care. Infants that require lengthy hospitalizations include those with chronic lung disease who have a prolonged need for supplemental oxygen, medical supervision and specialized nursing care.

At the same time the numbers of these infants have been increasing, the health care system has been increasingly stressed due to: (a) the expenses incurred by individuals requiring long-term or chronic care, including infants with chronic lung disease; (b) the expense involved in maintaining and upgrading facilities and equipment in acute care hospitals; and (c) the expense of providing long-term care in acute care facilities; and shortages of acute care beds. As a result there has been encouragement to establish and maintain early discharge programs.

The concept of early discharge programs for infants was supported by evidence from members of the health care team regarding the deleterious effects of prolonged hospitalization. One concern has been the interference with growth and development that occurs in hospitalized infants. Even though an attempt is made to appropriately stimulate and play with infants a home environment is never recreated. The intensive care units remain inadequate environments for normal growth and development (Jackson, 1986; Paulson, 1987). There may be sleep deprivation and sensory overload as well as the absence of consistent caregivers. One further limitation of the intensive care environment is the lack of mobility afforded to infants. The environment requires that infants stay in a restricted space limiting the opportunity for learning (Jackson, 1986).

Family development has been another concern for health care team members. There is family disruption when an infant experiences extended hospitalization. Parents may try to spend all their time at the hospital at the expense of any children at home. At the very least, parents spend time juggling their time between the home, the hospital and work (Paulson, 1987). Paulson (1987) states that an infant at home on oxygen therapy may still require a lot of time but the rest of the family can be included in the day-to-day activities.

One further concern with prolonged hospitalization is its effect on family-infant attachment. Initially, family-infant attachment may be limited due to separation, the severity of the illness, and equipment. This makes it difficult for parents to touch the infant and/or limits their ability to provide care for the infant (Isaacs, 1980; Paulson, 1987). According to Paulson (1987), even when the infant

is convalescing parents may be reticent to interact with the infant due to the fear that they may still lose him. Jackson (1986) also suggests that parents of hospitalized infants do not feel that the infant belongs to them. They have little control over decisions and few opportunities to interact privately with their infant. These circumstances can also impair family-infant attachment.

As the safety of early discharges was established groups of infants requiring supportive care were reviewed from the aspect of early discharge. However, as these infants were included in early discharge, problems were identified for the parents taking these infants home.

It was identified that taking any high-risk infant home was stressful and anxiety provoking for the parents (Sammons & Lewis, 1986). In order to minimize anxiety as much as possible when taking a high-risk infant home with supplemental oxygen it was considered critical to provide parents with a thorough teaching program to increase their knowledge and thereby control another potential source of anxiety (Jackson, 1986; Parsons, 1984; Paulson, 1987; Scherf, 1985). Although all of the articles reviewed insisted upon a teaching program none included an actual evaluation of the teaching the parents received. Therefore, it was difficult to document program effectiveness. Due to the increasing costs of health care (stated above) not only are early discharge programs encouraged, but documentation of their effectiveness is necessary to justify any costs that may be incurred.

It was the objective of this study to develop and evaluate the effectiveness of a parent education program for infants discharged home on supplemental oxygen. The study was designed to answer one question in particular: Is the education program effective for increasing the knowledge of the caregivers?

CHAPTER 2

Literature Review

It is the purpose of this chapter to review selected literature regarding discharge planning and teaching, evaluation of education programs, oxygen therapy in adults, oxygen delivery systems, oxygen therapy in infants, early discharge of infants, the discharge of infants home on supplemental oxygen, and principles of discharge teaching. The literature reviewed is primarily limited to American and Canadian sources.

Discharge planning and teaching

With the first documentation of infants discharged home on supplemental oxygen the need for discharge planning and parent teaching was also documented (Campbell et al., 1983; Fox, 1978; Glassanos, 1980; Guilfoile & Dabe, 1981; Koops et al., 1984; Pinney & Cotton, 1976; Sewell et al., 1986).

One of the earliest articles documenting specific instruction parameters for parents of infants discharged home on supplemental oxygen was by Glassanos (1980). Various professionals involved in the care of the infant formulated a care plan for each family. The nursing staff would then develop a teaching plan dealing with all the aspects of the care required by that particular infant. The expected outcomes for parents in each area were documented. Glassanos (1980) stated that areas to consider include disease process, medications, activity, complications, and

growth and development. She also indicated the importance of instruction for more than one member of the family.

There are two areas that this article did not address. The first was the actual method of instruction. A standardized teaching checklist was completed by nursing staff. There was no mention made of the methods of instruction used with the caregiver. It has been indicated that a teaching program should include more than one method of information delivery. These methods should have included discussion, instructional materials, demonstration and return demonstration, extended periods of independent caregiving by the family while in the hospital, as well as written materials to take to the home (Ahmann, 1986; Program Planning Guide, 1977). Since there was instruction by individual nurses there is no method to determine if the families received any standardized, consistent information.

The second area not addressed was evaluation. There was no mention of any follow-up of, or feed back from parents or nurses that would have indicated effectiveness or thoroughness of the instruction given. Many authors had indicated that evaluation was necessary to ensure safe, quality care in the home, to justify program costs and to identify and resolve problems or inadequacies in discharge teaching/planning (Ahmann, 1986; Dignan, 1986; Jessee & Doyle, 1984).

In 1983, Srokosz edited a discharge guide for infants who were going home on supplemental oxygen. This program included step-by-step discharge planning and teaching for parents and was aimed at the health care professionals involved with the infant. The program was very structured for the professional and left actual teaching of the parents up to each individual.

The discharge guide was thorough and clear, however it was intended for professional use and left actual parent instruction to the individuals caring for the family. As a result, the actual content may have varied according to the experience of the nurse, time constraints and differences in identification of priority material among those providing the education. Two pages of printed material were given to parents and briefly covered criteria for inclusion in the home oxygen therapy program, supplemental oxygen supply, risks of using oxygen in the home, observation of the baby, infections, and resuscitation. Due to the short nature of this information it did not provide much information on each of these topics. No evaluation of the effectiveness of the teaching was completed.

Catherine Parsons (1984) stated that some health centres had made home oxygen services available to infants and their families without providing essential discharge planning. She further stated that this "situation causes undue anxiety for the family and increases the risk of failure of the oxygen therapy program." (Parsons, 1984, p. 84). Parsons (1984) reviewed and supported the program for health professionals edited by Srokosz (1983) which outlined the essential components to be considered for families of infants to be discharged home on supplemental oxygen.

Goodman and Sauve (1985) documented concerns of the mothers of high-risk infants from a tertiary level neonatal intensive care unit. They found that the mothers of these infants were likely to feel overwhelmed by loss of control during the hospitalization of the infant. Stresses were also placed on the emotional, social and financial aspects of family life during this time. It was found that these

stressors did not decrease after discharge of the infant but increased. As a result it was anticipated that the needs of the mothers for support and guidance was great. All new mothers had significant concerns regarding their high-risk infants. These concerns included the areas of feeding, sleeping, appearance, and maternal-infant attachment. Study results indicated that in the group of high-risk infants there was the potential for ongoing problems post-discharge. These results provided valuable information regarding the discharge teaching content for the parents of high-risk infants as the sample sources were the same.

Groeneveld (1986) documented a program for sending infants home on supplemental oxygen. The program was developed in 1979 due to consideration of the benefits of home oxygen therapy for infants. The staff at the Hospital for Sick Children in Toronto, Ontario developed criteria for discharge on home oxygen therapy. An evaluation of the homes of infants was also completed. If an infant and his/her family met all criteria, instruction took place. Teaching included instructions for setting up, maintaining and problem solving with oxygen equipment, potential problems with the infant and infant resuscitation. The information was also provided in written form for parents to take home. All infants were readmitted to hospital every three weeks for reassessment. Groeneveld (1986) stated that benefits to sending the infants home on supplemental oxygen included weight gain, increased parental involvement, earlier integration of the infant into the family and financial savings. However, as stated, no formal evaluation of the program had been done. The evidence gathered indicating a successful teaching program was subjective and included increasing the confidence of the mother, enhancing

mother-infant attachment and increasing the desire to have the infant home during readmissions to the hospital.

Paulson (1987) documented areas that were taken into account when infants were to be discharged to home on supplemental oxygen. She described the benefits of home care including reduced financial costs and an environment providing the infants with a ""normal" home environment and socialization" (Paulson, 1987). While the infant was in hospital there remained an alteration in parenting and attachment that could be improved upon with discharge to home. The final issue considered by Paulson (1987) was the risk of hospital acquired infections versus the risks at home. Paulson (1987) indicated that the risk is greater in the hospital for immunocompromised patients. This was partially due to the number of other children present.

This article also discussed criteria both for sending an infant home on supplemental oxygen and for discharge teaching. There were factors that were considered independently for the patient, the family and the primary care physician. Areas identified for family teaching were well child care, medications, illness/respiratory distress, CPR, and oxygen equipment. The author suggested that the best method of teaching families about oxygen equipment was through "hands on" experience. It was also suggested that parents spend at least one twenty-four hour period with the infant and oxygen equipment before discharge home. Paulson (1987) stated that with proper discharge teaching, follow-up teaching and support, families and infants could manage well at home. Although this article considered the important components of criteria for discharge with supplemental oxygen, and

topics to be included in instruction for parents, it did not address how to present the information and did not formally address evaluation of the instruction for effectiveness.

Many authors state that prior to discharge, family needs for instruction are assessed and addressed. In this way home management of the infant can be a positive experience. Discharge planning and teaching can assist in minimizing problems and stressors (Ahmann, 1986; Arenson, 1988; Jackson, 1986; Paulson, 1987; Wagner & Segall, 1987).

The Ad Hoc Task Forces on Home Care of Chronically Ill Infants and Children published guidelines for home care in 1984 (Ad Hoc Task Forces, 1984). It was stated that hospitalized individuals often lacked normal interpersonal and social relationships with family. These relationships were seen as necessary for growth and development. The Task Forces identified the goal for home care as "the provision of comprehensive, cost-effective health care within a nurturing home environment" (Ad Hoc Task Forces, 1984, p. 434). Identified in the guidelines was the need for comprehensive planning by a multidisciplinary team for each family. The guidelines stated that criteria for home care should be established based on the existing available program resources, potential benefits, costs and risks. Criteria were included for the patient, the family and the community. The Task Forces included a statement that considered education. The guidelines suggested that family and support caregivers be taught the home care program. They also supported the concept of family care of the child before discharge with minimal

health professional involvement. Finally, the Ad Hoc Task Forces outlined a program evaluation and outcome component to assess program outcomes.

An article by Arenson (1988) stated that although discharge planning and teaching were effective in decreasing parental anxiety and were essential to continued quality care for the infant, discharge planning was often viewed as a difficult problem by health professionals. In her literature review, Arenson (1988) cited sources that maintained that routine teaching should be done consistently so that all participants receive the same information. She further stated that "standardizing the information we provide parents improves our ability to prepare them for home care" (Arenson, 1988, p. 51).

A summary of the literature reviewed indicated a lack of formal evaluation of the teaching programs established for parents of infants discharged home on supplemental oxygen. Formal evaluation was not completed for any of the programs reviewed. One further area with limitations was that of program planning. It did not always indicate the inclusion of principles of adult learning and standardized, routine teaching for families.

Evaluation of teaching programs

Several authors had stated that evaluation of programs is essential in order to ascertain whether or not they improve health outcomes and contribute to the optimal delivery of health care (Arenson, 1988; Burns & Grove, 1987; Holm & Llewellyn, 1986; Jessee & Doyle, 1984; Rehr, 1986).

Jessee and Doyle (1984) stated that by evaluating or auditing discharge planning/teaching programs, shortcomings may be discovered, as may the problems leading to those shortcomings. They performed an audit demonstrating the outcomes related to a discharge teaching/planning program. As a result improvements were suggested for the discharge planning program to increase its effectiveness.

A study was done by Isaacs (1980) regarding evaluating the teaching done with parents of high-risk infants in their homes. A questionnaire which the parents received requested general information about the infant and hospitalization, as well as attitudes toward the birth, the baby, the teaching and support received. The questionnaire also asked parents to comment on the specific method and mode of teaching utilized. The results indicated that the teaching decreased anxiety and enhanced their ability to care for the infant. She also found that it reduced the number of phone calls to both the hospital and the physician caring for the infant after discharge.

In a thesis from the University of Calgary regarding the concerns of mothers of high risk infants a significant number of mothers of high risk compared to a control group of infants felt that discharge teaching was either not done or was not done to their satisfaction (Goodman, 1983). Goodman (1983) suggested that discharge teaching may have been either inappropriately timed, when mothers were not able to focus on the information, or was lacking in content. She suggested re-evaluating the current discharge education programs for parents of high-risk infants.

Another thesis completed at the University of Calgary by Parker-Loewen (1986) studied mother/pre-term infant pairs to establish the effects of short-term coaching on interaction. The coaching sessions took into consideration the individuality of each mother and followed a general outline. Topics included the ranges of stimulation for each particular infant, responsiveness to infant cues, active stimulation of the infant using appropriate methods for the development, interests, and attention span of the infant, and responding to infant vocalizations. The coaching did not significantly enhance mother infant interaction but it did make mothers more knowledgeable about infant development. This could have had potential benefits by allowing the parent(s) to interpret the infant behaviors more accurately. This could have led to an easier integration of the infant into the family unit. A question to be considered was whether or not teaching programs outside the family are actually effective in changing behaviors in the home.

Dignan (1986) indicated further support for evaluation of health education programs in all areas. He stated that program evaluation allows answers to be found for programs in the area of cost effectiveness. Since financial constraints had become an issue in the area of health care, it was important to evaluate programs. If a program was not providing the desired outcomes, it was essential to determine a more effective way of obtaining them. Ongoing evaluation could identify whether or not adequate discharge planning was being carried out consistently. Problems could be identified and resolved before they compromised quality of care (Dake, 1984). The purpose of health program evaluation was to justify costs and improve health outcomes (Dignan, 1986).

According to Ahmann (1986) evaluation of discharge planning/teaching was necessary so home care by the parents could be safe and practical. Parents were useful for contributing feedback regarding the usefulness of information and the suitability of the method(s) of presentation. Evaluating the effectiveness of discharge teaching was essential to ensure that the information provided remained relevant to the home care situation (Arenson, 1988). In the area of effectiveness of educational methods it was stated that "If one cannot provide assurance on the basis of prior research, one must evaluate to be accountable" (Green, Kreuter, Deeds, & Partridge, 1980, p. 133).

Uses of oxygen therapy

Oxygen therapy was first utilized for patients with pneumonia in the 1920 - 1930s (Block, 1979; Openbrier, Hoffman, & Wesmiller, 1988). During the years 1930 - 1960 supplemental oxygen was used in an attempt to relieve, or rehabilitate adult persons with crippling respiratory disease (Block, 1979; Openbrier et al., 1988). Supplemental oxygen administration was expensive and required either an oxygen tent or specially adapted room (Block, 1979; Openbrier et al., 1988).

By the 1950s ambulatory supplemental oxygen had been developed, however, it was very costly and inefficient (Block, 1979). This and concerns about oxygen toxicity, carbon dioxide retention and carbon dioxide narcosis, safety, the weight of portable tanks (7.5 kg) and the limited capacity of light-weight tanks (Openbrier et al., 1988) were operational in the lack of oxygen as therapy for ambulatory patients.

Nevertheless, the effects of oxygen therapy on patients began to be studied in

adult patients with chronic obstructive lung disease (COPD). This group was chosen because it compromised "the largest, most homogeneous group of patients with chronic hypoxemia" (Anthonisen, 1983, p. 519).

In the 1960s studies regarding efficacy and effectiveness of home oxygen therapy were done (Block, 1979). However, many concerns regarding these studies were raised. Common concerns were the lack of controlled studies and small sample sizes (Anthonisen, 1983; Block, 1979; Flenley, 1985). Even so, these studies tended to support decisions to use continuous oxygen therapy in adults with COPD. These patients tended to have symptoms related to their chronic hypoxemia which included pulmonary hypertension, right sided heart failure, polycythemia and exercise intolerance with increasing hypoxemia (Anthonisen, 1983; Block, 1979). The initial studies, although not without flaws, did indicate reduced pulmonary hypertension, and polycythemia in COPD patients receiving continuous oxygen therapy. More importantly, the early studies established the safety of oxygen therapy. Carbon dioxide narcosis did not occur, there were no associations of oxygen therapy with lung function changes due to oxygen toxicity, and there was no increase in the occurrence of fire and explosion (Anthonisen, 1983; Block, 1979). Other reported benefits to home oxygen therapy included fewer hospitalizations, decreases in the incidence of aggravated right sided heart failure, and improvement in IQ, memory, concentration and coordination with long-term therapy (Anthonisen, 1983).

Two studies done in the early 1980s were considered very important for documenting the advantages of oxygen therapy. By this time adequate home

oxygen systems had been developed and patients who were utilizing home oxygen therapy could be better studied (Anthonisen, 1983; Flenley, 1985; Openbrier et al., 1988; Petty, 1985). These studies were controlled, they had large sample sizes and the sample groups were comparable. One study was a multicentre trial in Britain, the other was a multicentre trial in the United States. These two studies effectively demonstrated the benefits of continuous, low-flow oxygen therapy rather than intermittent or no therapy. Intermittent therapy was considered to be 15 or fewer hours in a 24 hour period. Continuous therapy was considered to be 19 or greater hours of oxygen therapy in a 24 hour period. Low-flow oxygen requirements were considered to be 0.5 litres per minute to three litres per minute (Anthonisen, 1983; Flenley, 1985; Openbrier et al., 1988). The most important conclusion drawn from these two studies was that continuous, low-flow oxygen therapy was effective in improving the survival rate in hypoxemic COPD patients (Anthonisen, 1983; Flenley, 1985; Openbrier et al., 1988).

In summary, the early studies of oxygen therapy including the two multicentre trials completed in the early 1980s established both the safety and efficacy of oxygen therapy for adults with COPD. Some of the authors made statements indicating that, even though no studies had been done, there was no reason to believe that oxygen therapy would be any less effective in other lung diseases resulting in severe hypoxemia (Anthonisen, 1983; Flenley, 1985; Openbrier et al., 1988; Petty, 1985).

Oxygen delivery systems

Early in the 1920s the oxygen tent was developed and utilized for patients with pneumonia. Oxygen therapy continued to be utilized for "respiratory cripples" and in the 1960s an "enriched oxygen room" (Block, 1979, p. 72) was utilized for these patients (Openbrier et al., 1988). However, these methods of oxygen provision were expensive and had little practical applicability to long-term oxygen provision.

By the 1950s, oxygen was supplied by large oxygen tanks or cylinders (Block, 1979; Openbrier et al., 1988). These cylinders were extremely heavy (70 kg), and stored oxygen at very high pressures due to its compressed nature. Such pressures created a safety hazard and patients were considered "home-bound" (Openbrier et al., 1988). Tanks were large, but capacity was limited so repeated deliveries or many tanks were required. Advantages to compressed oxygen included tanks that did not vent so no oxygen was lost, delivery of one hundred percent oxygen, a wide possible range of litre per minute flows and economy (Openbrier et al., 1988). This method continues to be utilized as a method of oxygen delivery.

Subsequent to the development of compressed oxygen tanks, oxygen concentrators were developed. Concentrators utilized room air removing nitrogen, water vapor and hydrocarbons thus resulting in oxygen delivery of greater than ninety percent oxygen. The higher the flow rate (litres per minute) the lower the oxygen concentration delivered. These systems did not need refilling and were the least expensive. They were considered to be the most effective method of oxygen delivery (Flenley, 1985). However, they were only appropriate for home use as

they required a continuous electrical supply (Openbrier et al., 1988). This method of oxygen provision continues to be used.

The third method of oxygen delivery developed was the liquid oxygen system. This system was initially utilized in the late 1960s (Block, 1979). The oxygen was cooled so it was compatible with low pressure storage in smaller, lighter containers. The small, portable containers developed weighed only three to five kilograms. Liquid oxygen portable tanks were easily and safely refilled from the larger tanks (Openbrier et al., 1988). Liquid oxygen was the most expensive of the oxygen delivery systems. This system also vented small amounts of oxygen if not used. Since the initial development of these systems liquid oxygen has become the cheapest method of oxygen delivery in the home (Seville & Walsh, 1984).

Questions remained regarding how to deliver oxygen to the patient. Initially, masks were utilized, however they were bulky and interfered with activities of daily living (Block, 1979). As a result, nasal prongs were developed which were practical, safe in the ambulatory patient, inconspicuous, delivered variable flow-rates of oxygen and were tolerated well by the patient. Another advantage to nasal prongs was that they could be utilized with any of the available oxygen delivery systems (Block, 1979). According to Flenley (1985) oxygen was best delivered to patients via nasal prongs rather than masks. Prongs almost always stayed in place, where masks were often dislodged, especially during sleep.

Oxygen therapy in infants

Chronic hypoxemic lung disease of newborn infants was first documented in 1967 and continued to be documented over the years. This disease occurred in infants who received supplemental oxygen and assisted ventilation for severe hyaline membrane disease (Fox, 1978; Jackson, 1986; Northway, 1979). Hyaline membrane disease or respiratory distress syndrome (in pre-term infants) was a developmental disorder of the pulmonary system resulting in surfactant deficiency leading to atelectasis, decreased lung compliance, and increased pulmonary vascular resistance. These events caused hypercapnia and hypoxemia (Korones, 1986) and often required assisted ventilation with supplemental oxygen for correction (Northway, 1979).

The chronic lung disease, called bronchopulmonary dysplasia (BPD), was associated with oxygen delivered under pressure over time to immature lung tissue, as well as other factors (Fox, 1978; Korones, 1986; Philip, 1975). Bronchopulmonary dysplasia was documented in varying degrees from mild disease requiring little treatment, to severe disease requiring multiple therapies (Fox, 1978). Infants with moderate to severe BPD demonstrated pulmonary hypertension and right sided heart failure, hypoxemia and hypercarbia (Abman, Wolfe, Accurso, Koops, Bowman, & Wiggins, 1985; Fox, 1978; Korones, 1986). With appropriate supportive treatment, infants with BPD who progressed to a stable state off a ventilator had a good prognosis. Supportive treatment included supplemental oxygen therapy for infants with hypoxemia, diuretics, bronchodilators, fluid and nutritional management and judicious use of antibiotics (Fox, 1978; Korones, 1986). The

clinical signs and symptoms of bronchopulmonary dysplasia gradually resolved over a period of one to three years although functional signs were long-lasting.

Early discharges of infants

In the 1960s many practices regarding neonatal care underwent examination with subsequent revisions. Revisions included the organization of nurseries, infection control practices, medical coverage, health care team development, and parental visitation. When the new practices were successful a move was made to investigate discharging low birth weight infants earlier than before (Bauer & Tinklepaugh, 1971).

There were several considerations for determining at what weight infants could safely be discharged. Two concerns were the quickly increasing costs of specialized, and lengthy hospital care and the risk of hospital acquired infection in patients with extended hospital stays (Bauer & Tinklepaugh, 1971; Berg & Salisbury, 1971; Lefebvre, Veilleux, & Bard, 1982). Other concerns included a delayed and/or altered mother-infant relationship related to prolonged separation, and overcrowding and understaffing of nurseries contributed to by extended lengths of stay for stable infants who were simply growing (Berg & Salisbury, 1971; Lefebvre et al., 1982).

Prior to 1970 infants born with low birth weights were generally cared for in the hospital until they weighed close to 2500 grams even when they did not require any specialized care (Bauer & Tinklepaugh, 1971; Berg & Salisbury, 1971). One program which promoted earlier discharge of these infants was mentioned by Bauer nd Tinklepaugh (1971). It was this program, which evaluated sending infants home,

in a rural setting, half of whom weighed less than 2200 grams which stimulated examination of early discharge in the urban centres.

Several studies have since been done to determine the safety of early discharge home for low birth weight babies (Bauer & Tinklepaugh, 1971; Berg & Salisbury, 1971; Brooten et al., 1986; Dillard & Korones, 1973; Lefebvre et al., 1982). The reasons for conducting these studies included those mentioned above, as well as concerns regarding evidence suggesting the neonatal intensive care environment contributed to auditory, visual and motor difficulties, and the association between prolonged hospitalization, child-abuse, failure to thrive, and "parental feelings of inadequacy" (Brooten et al., 1986, p. 934).

The early studies done in the 1970s indicated that infants could be sent home earlier, as a weight of less than 2200 grams was not an indication to prolong hospitalization. All studies utilized some discharge criteria including, stable vital signs, corrected or stable anomalies, parental instruction, prearranged post-discharge care, parental readiness and satisfactory intake by the infant (Bauer & Tinklepaugh, 1972; Berg & Salisbury, 1971; Brooten et al., 1986; Lefebvre et al., 1982). All the studies indicated that early discharge home was safe. There were no indications that infants did not grow or gain weight, hospital stays were significantly reduced, there were no changes in hospital readmissions or emergency department utilization and most parents were able to care for the infants at home with few difficulties (Bauer & Tinklepaugh, 1972; Berg & Salisbury, 1971; Brooten et al., 1986; Dillard & Korones, 1973; Lefebvre et al., 1982). The conclusions were that early discharge for low birth weight infants was safe for the infant and contributed to decreasing

the length of hospital stays and therefore costs, and facilitated nursing coverage during periods of restricted staffing.

Discharge of infants on supplemental oxygen

One of the earliest studies dealing with infants sent to their homes on supplemental oxygen was done by Pinney and Cotton (1976). These authors indicated that although the use of supplemental oxygen at home by adults had been addressed previously (Anthonisen, 1983; Block, 1979; Flenley, 1985; Openbrier et al., 1988), there was little or no mention of its use by infants or children. They described six infants who were selected to be discharged from the hospital to their homes on continuous oxygen therapy. The home oxygen therapy was intended to shorten hospital length of stay and, more importantly, to introduce the infant into his home to facilitate parent-child relationships and infant development. They focused on infant health parameters such as weight gain, PO_2 (partial pressure of oxygen in the blood) and chest x-rays. The infants suffered no complications from being at home on supplemental oxygen (Pinney & Cotton, 1976). Pinney and Cotton indicated that parents did receive some instruction prior to discharge, although the study was more specifically concerned with infant responses. They indicated the need for increased parent teaching prior to discharge. However, they did not indicate formalization or evaluation of the instruction. Parents indicated that the experience of having the infant at home outweighed any anxiety related to utilizing oxygen therapy. From their observations of infants discharged home on

oxygen Pinney and Cotton (1976) felt that the use of home oxygen therapy with infants was safe and useful.

This concept was endorsed by Fox (1978) who summarized the available therapies for the outpatient management of bronchopulmonary dysplasia. These therapies included continuous oxygen provided at home via nasal catheter.

In 1980, Glassanos indicated negative impacting factors in neonatal intensive care units for parent-infant attachment and infant development (Jackson, 1986). Neonatal intensive care units did not promote growth and development because they lacked opportunities for mobility, interaction and learning, and provided sensory overload and/or sleep deprivation. Multiple caregivers were common, contributing to the undesirable environment, increasing the possibility of nosocomial infection, especially in infants with compromised respiratory function (BPD), and limiting parental control and private interaction with the infant (Jackson, 1986).

Paulson (1987) stated that infants should be in their own homes, with their own toys, in a familiar environment. They should be in their own bed and bedroom with siblings and parents with whom they could socialize. Koops, Abman and Accurso (1984) stated that attachment of parents to the infant was enhanced by the infant being home. They also indicated that the development of the infant was facilitated and improved after being home.

Home care benefitted parents by decreasing trips to the hospital and decreasing frustration from dealing with multiple health care providers (Glassanos, 1980). It was also indicated that all aspects of infant care could be learned by willing parents and indicated goals of parent teaching. The areas of teaching included:

administration of medications, administration of supplemental oxygen, proper suctioning technique, newborn/infant care, physiology of chronic lung disease and other areas considered pertinent to successful outcomes. Glassanos (1980) stated that supplemental oxygen dependent infants "thrive better in their own homes than in the hospital" (Glassanos, 1980, p. 45) and maintained that with planning and parent teaching oxygen dependent infants could successfully be discharged to their homes.

Guilfoile and Dabe (1981) stated that at the time of their study most sources of information regarded nasal catheter oxygen therapy for infants inappropriate. However, due to the study done by Pinney and Cotton (1976), Guilfoile and Dabe initiated a trial of this therapy. They studied six infants who had been confined to oxygen tents or hoods until the time of the study. They documented $tcPO_2$ (transcutaneous oxygen) values for both head hood or tent and nasal catheter during various infant states. The duration of oxygen therapy via catheter and the tolerance and outcome of the infant was monitored (Guilfoile & Dabe, 1981). The study indicated advantages for the infant related to nasal catheter for delivery of oxygen which included a more stable FiO_2 (inspired oxygen concentration) during some activities which led to a more stable $tcPO_2$ reading. During other activities the catheter provided oxygenation comparable to that in hoods or tents. Some improvement in infant motor abilities and mental development was also noted with oxygen therapy via catheter. Guilfoile and Dabe (1981) stated that the nasal catheter method of oxygen delivery in infants made home management an

alternative to hospital care and facilitated increased parental involvement by allowing greater freedom of movement.

A study done in Canada (Campbell, Zarfin, Groeneveld, & Bryan, 1983) followed 51 infants who were oxygen dependent. All infants received low-flow oxygen therapy via nasal catheter. Thirty-five of these infants were discharged home on supplemental oxygen. The authors reviewed the clinical data of the infants and the outcome of each infant. Campbell et al., (1983) indicated that parents underwent a two week instruction period including topics such as symptoms of hypoxia, and handling and care of equipment. It was found that delivery of supplemental oxygen by the catheter method allowed increased contact between the infant and caregivers. This allowed more "positive relationships to develop within the family" (Campbell et al., 1983, p. 797). These investigators indicated that the home oxygen program was also of benefit because earlier discharge home resulted in financial savings for the parents, hospital and health care system. However, there was no evaluation component to establish the completeness of parent instruction and/or parent perceptions of the teaching received. Optimal patient (parent) teaching can best be accomplished through the evaluation of such teaching.

Abman, Accurso and Koops (1984) monitored the course of 23 infants who were discharged home on supplemental oxygen. This study was initiated due to a lack of documentation on the clinical course of infants on, and the efficacy of home oxygen therapy. The authors documented growth parameters, physical examinations, and $tcPO_2$ measures during the first year of life. The duration of supplemental oxygen therapy was also documented. Infant outcomes indicated a consistent

improvement in measurement parameters while on home oxygen therapy even though the infants grew poorly and often required rehospitalization. Abman et al. (1984) concluded that home oxygen therapy was a safe treatment modality for infants with bronchopulmonary dysplasia, provided there were frequent follow-up evaluations for each infant.

Sauve, McMillan, Mitchell, Creighton, Hindle and Young (1989) completed a study on the outcomes of infants discharged home on supplemental oxygen. Morbidity outcome measures included growth parameters, neurologic measures, cognitive assessments, speech assessments, hearing loss, and ophthalmologic examinations. These follow-up measures indicated some long-term problems associated with the infants who were discharged home on supplemental oxygen. However, the study also indicated that there was a high degree of parental acceptance of the home oxygen therapy as well as the avoidance of some hospital days for the infants. A decrease in the number of hospital days could have impacted on the medical cost of these infants. It was also suggested that shorter hospital stays could possibly decrease the negative social impact associated with prolonged hospitalization.

Thilo, Comito and McCulliss (1987) conducted a study to assess parental acceptance of home oxygen therapy with infants. The authors conducted a telephone survey of parents of infants home on supplemental oxygen using a questionnaire developed for the study. The questionnaire assessed the economic and social impact of home oxygen therapy on the family. All study participants had met the same criteria for discharge with supplemental oxygen and had received

some discharge instruction. The results of this study indicated that most of the parents involved considered home oxygen therapy for their infant successful. Parents also indicated that they felt their infant grew and developed more normally at home. There was no mention of any evaluation of the parent instruction given.

By 1986, Sewell, Holsclaw, Schidlow, McGeady, Gerger and Kolb indicated that satisfactory techniques for administering oxygen to infants in the home had been established. As a result, the use of supplemental oxygen in the home had increased. Sewell et al., (1986) also indicated that while the use of oxygen therapy in the homes of infants had increased the documentation of the outcomes of such use was limited. The authors of this paper suggested some basic considerations for health care providers contemplating the use of oxygen therapy for children in the home. These considerations included adequate planning before discharge, criteria for administration of supplemental oxygen, and areas of assessment for the ability of families to care for the child at home.

Groothius and Rosenberg (1987) studied the effect of home oxygen therapy on infant weight gain. Lack of weight gain had been a problem in infants with bronchopulmonary dysplasia requiring oxygen therapy. It was indicated that poor weight gain had been associated with long-term respiratory difficulty. Twenty-two infants were studied retrospectively. All infants were discharged from the N.I.C.U. on oxygen therapy. All families received instruction regarding supplemental oxygen use and all infants were followed up a least once each month. Each infant was evaluated on many parameters as well as length, weight and head

circumference. The growth parameters were consistently measured by the same individual.

Fifteen infants received continuous home oxygen therapy. These infants had better weight gain than seven infants who were abruptly discontinued from oxygen therapy. These seven infants began again to gain weight at the same rate as the other infants when supplemental oxygen was reinstituted.

Groothius and Rosenberg (1987) concluded that home oxygen therapy had an important role in the treatment of infants with bronchopulmonary dysplasia. However, this statement was made with qualifying remarks regarding thorough assessment of families before selection for such a program and consistent, careful follow-up care by (a) physician(s).

A study done by Young, Creighton and Sauve (1988) assessed the needs of families of infants discharged home on supplemental oxygen. The study was conducted by interviewing families and health professionals with regard to four areas of need. Results of the study indicated that areas of need as identified by parents were: 1) More information on the impact of disease on all body systems; 2) Structured, unrushed cardiopulmonary resuscitation teaching; 3) Information on infant health and weight gain; 4) Mobility of oxygen equipment. Health professionals who were interviewed indicated that there were deficiencies in the information given to parents at discharge, and indicated that more time should be spent on discharge teaching. The authors also identified some implications for nursing. They suggested that discharge teaching should begin well before discharge and should also be sent home in written form. The written information could

contain items related to changing needs including community resources and support services.

Principles of teaching for discharge

Shorter lengths of stay demanded more attention for discharge planning and teaching to ensure patients received the care necessary in hospital and after discharge (Rehr, 1986). Several basic principles were suggested as essential for planning discharge teaching. These principles included routine, standardized teaching measures which ensured that all patients received the same information (Arenson, 1988). It has also been stated that successful education/teaching programs included educating more than one family member, providing written material of the information given orally, discussion, demonstration and a return demonstration (Ahmann, 1986; Arenson, 1988). These varied methods of teaching were based on principles of adult learning. "Each adult is a unique individual and the product of his experience over time" (Program Planning Guide, 1977, p. 16). As a consequence it was essential to take into consideration adult learning principles when considering the design and/or implementation of an education program. These principles included:

(1) The type of material to be learned influences learning. For example, material that is more meaningful to the learner is more readily learned.

(2) Reinforcement. Reinforcement that occurs often and appropriately enhances adult learning.

(3) Immediate knowledge of results. This principle contributes to the meaningfulness of any participation by the learner.

(4) Active participation. Active participation encourages learning of content and facilitates learning by allowing individual involvement to the extent desired by each participant.

(5) Provide opportunities for practice. When new behaviours are to be learned the success of the learning is increased if learners are able to immediately put into practice what they have learned.

(6) The environment must be conducive to learning. An environment that is not appropriate (for example, one that is too hot, poorly lit or too small) distracts learners from the material to be learned (Dickenson, 1973). Depending on the domain in which learning was desired different methods of instruction were recommended (Dickenson, 1973). Another principle was that individuals had different learning styles and learned best by methods matching those styles. Adults learned what was important to them and what directly applied to them.

As a result, it was important to consider the learning environment, content, methods of presentation, sequencing of information and evaluation when designing an education program (Dickenson, 1973; Huckabay, 1980). Evaluation was essential because learning is not directly observable and so needed to be measured indirectly to determine the effectiveness of the teaching program including the kinds of changes taking place and the kinds of errors made (Dickenson, 1973; Huckabay, 1980).

Summary

All of the authors reviewed in the area of discharge planning and teaching supported the view that planning and teaching are valuable for decreasing parental anxiety and stress. Appropriate preparation of parents can make the experience very positive. However, none of these programs included a formal evaluation to determine the effectiveness of the teaching.

Further literature reviewed indicated the need for evaluation of health education programs to: (a) justify costs; and (b) improve health outcomes and deliver optimal health care. Evaluation can help in identification of problems associated with less than desirable outcomes in the parameters to be assessed.

Information regarding oxygen therapy in adults was reviewed. Supplemental oxygen was first used in a limited capacity in the 1920 to 1930s. As technology advanced and oxygen delivery systems improved oxygen therapy was tried as a treatment for adult patients with chronic obstructive lung disease with hypoxemia. These early studies established the safety of oxygen therapy for adults at home.

Two controlled studies done in the 1980s provided information demonstrating the benefits of continuous oxygen therapy for adults with chronic obstructive lung disease resulting in hypoxemia. It was also suggested that oxygen therapy should be effective in other types of lung disease resulting in hypoxemia (Anthonisen, 1983; Flenley, 1985; Openbrier et al., 1988; Petty, 1985).

The literature reviewed included the available oxygen delivery systems. Systems discussed were the compressed oxygen system, oxygen concentrators and

liquid oxygen. At this time liquid oxygen was considered to be the cheapest, most effective system for supplemental oxygen delivery for adults who were ambulatory.

A brief review of chronic hypoxemic lung disease (BPD) in infants was done and indicated that this disease was similar to chronic obstructive lung disease in adults. Both resulted in hypoxemia, hypercapnia, pulmonary hypertension and right sided heart failure. Supportive treatment for infants with BPD included continuous oxygen therapy.

As a background to the discharge of infants home on supplemental oxygen, information on early discharge of infants was reviewed. Reasons for early discharge of stable, low birth weight infants included enhanced parent-infant attachment, increasing costs of hospitalization, the risk of hospital acquired infection, and overcrowding and understaffing in intensive care nurseries. Studies were completed in the 1970 - 1980s which established the safety of early discharge home of low birth weight infants. Reduced hospital costs and no changes in hospital readmission rates or emergency department utilization were documented.

The literature regarding infants discharged home on supplemental oxygen by nasal catheter was reviewed. These studies and articles tended to deal with the effects of this form of therapy on infant outcome. All, however, made mention of the need for parents to receive some teaching prior to discharge. Consistent arguments for the initiation of this form of therapy for infants included: (a) decreasing length of stay in hospital, and so, decreasing financial costs; and (b) facilitating family relationships, parent-infant interaction and infant growth and development.

A review of the literature that was concerned with teaching parents of infants discharged home on supplemental oxygen indicated that there are several principles that are important for the success of an education program. These include early discharge planning and teaching, consistent teaching among families, areas to be considered for instruction, and instructing more than one caregiver for each family.

CHAPTER 3

Method

The content of this chapter includes the research question, study design, selection of subjects, education program construction, measurement tools, reliability and validity, data collection procedures, analyses of data and limitations of the study.

Research question

The purpose of this study was to evaluate the effectiveness of an education program developed for caregivers of infants who were discharged home on continuous low-flow supplemental oxygen. The research question was: Is the education program effective for increasing knowledge of caregivers?

Study design

In this study a one-group pre-test/post-test design was used. The study subjects, physicians, neonatal intensive care unit and infant home monitoring clinic staff were cooperative with this approach. This study was also approved by the Foothills Hospital Research and Development Committee, the Nursery Management Committee and the Conjoint Medical Ethics Committee for the University of Calgary. Using the one-group pre-test/post-test design it was possible to study an

entire cohort (over one year). The cohort comprised a unique group for which little information has been published regarding education.

The education program regarding home oxygen therapy for infants and the evaluation tools were developed for this study (Appendices A and B). A pre-test (evaluation of knowledge tool) was administered, the education program was presented, and a post-test (evaluation of knowledge tool) was given, as well as a program evaluation checklist. Four to six weeks post-discharge a delayed post-test (evaluation of knowledge tool) and satisfaction with parenting questionnaire (Ragozin, Basham, Crnic, Greenberg, & Robinson, 1982) were administered. All participants were evaluated twice, once before discharge and once four to six weeks after the actual discharge date.

Selection of subjects

All parents of infants who were to be discharged from Foothills Hospital Neonatal Intensive Care Unit on supplemental oxygen were considered to be eligible for participation in the study. The charge nurse of the unit offered parents the option of being included in the study. The criteria for admission to the study included: (a) an infant to be discharged home on continuous low-flow supplemental oxygen; and (b) (a) parent(s) willing to participate in the study.

During the period of data collection 10 infants were discharged home on supplemental oxygen and met the study criteria. All parents agreed to participate in the study resulting in a sample size of 18. The sample was considered to be representative of this population of parents because all of the infants discharged

home from this neonatal intensive care unit on supplemental oxygen, over the one year period, were included in the sample.

This was a geographically-based sample which included all infants discharged home on supplemental oxygen from a tertiary level, regional neonatal intensive care unit. This unit serves Southern Alberta, an area with 19,000 births each year. Recruitment of subjects was limited to this tertiary level neonatal intensive care unit since a number of confounding variables would have been introduced with the inclusion of level II neonatal units or the pediatric service of the Alberta Children's Hospital, both of which occasionally send infants home on supplemental oxygen. Those confounding variables include the teaching provided by other hospitals and the number of visits to the Infant Home Monitoring Clinic. Infants discharged home from Alberta Children's Hospital on home oxygen therapy have generally already been at home on supplemental oxygen. Further influencing factors may have included the differences in the learning environment as well as in medical and nursing practices among hospitals and the number of infant readmissions.

The education program

The target group for the education program (Appendix A) was narrowly defined as the parents of infants to be discharged home on supplemental oxygen. This group of parents had been identified as needing structured teaching specific to the concerns of taking an infant home on supplemental oxygen (Glassanos, 1980; Srokosz, 1983; Young et al., 1988). The topic taught was infant and family care for parents (caregivers) of infants who were discharged home on continuous

low-flow oxygen therapy. Education focused on physical characteristics and the care necessary for an infant on supplemental oxygen. Other teaching included psychosocial development of the infant, parental needs, oxygen equipment and cardiopulmonary resuscitation. These infants were not routinely discharged home with apnea monitors.

When developing the program the intended audience was taken into consideration. It was identified that the learners would have varied educational backgrounds and differing learning styles (Dickenson, 1973; Program Planning Guide, 1977). They would have some information regarding the physical care of infants as well as some exposure to the use of continuous low-flow supplemental oxygen in the hospital. The audience was considered to be motivated due to personal interest in the topic. The audience was also considered voluntary as families were only considered for infant home oxygen therapy if they were interested and agreed. Therefore, motivation was considered to be high.

This education program was not meant to replace the routine discharge teaching done in the unit. It was to be a supplement to enhance learning with the intent to review and build on old knowledge, as well as present new information.

The program was developed according to principles of adult learning and teaching strategies. The process of problem solving is unique and individualistic (Dickenson, 1973) and therefore, it was appropriate to incorporate three instructional media (booklet, videotape and practical session) to provide varied opportunities to learn. The principle of meaningfulness of the content to the learner (Program Planning Guide, 1977) was also considered, as the program was based on learner

needs. To encourage participation and motivation the content and goals of the program were introduced at the beginning of the program. This strategy was used to prepare the learners for participation in the program.

Active participation was a learning principle incorporated to increase retention of new knowledge (Program Planning Guide, 1977). This was done through questions for the learners after each section of the booklet, the opportunity for questions from the learners throughout, and the opportunity for discussion which followed the videotape. The practical session for the learners also involved active participation. The presentation of information in three different forms took into account different styles of learning among participants. This multiple media presentation also served to reinforce the information presented.

The incorporation of a practical experience assisted by a resource person was a strategy used to actively involve the learner. This portion of the program allowed the learner to experience his/her own infant. It may have increased the relevance of the information for the learner and thereby have increased motivation and enhanced learning (Dickenson, 1973; Huckabay, 1980). The inclusion of active participation throughout the program allowed learning to be used immediately. This possibly increased the length of retention and the likelihood of application (Program Planning Guide, 1977).

The opportunities for discussion and questions incorporated the principle of feedback for the learners (Program Planning Guide, 1977). The accuracy of comments or answers to questions were indicated immediately. According to the Program Planning Guide (1977) and Dickenson (1973), responses that were

reinforced immediately led to an increase in the permanence of learning. Immediate feedback also indicated progress to the learner. "Knowledge of results motivates the learners through recognizing their contributions, through validating that they are on the right track, through helping to identify the additional knowledge or skill that might be needed" (Huckabay, 1980, p. 349).

Measurement tools

Evaluation of knowledge tools. Data were gathered by means of two evaluation tools administered at three time periods. The evaluation tools were constructed for the purpose of evaluating the learning obtained by subjects from the education program. Two evaluation tools were constructed in order to decrease the test-retest effect of using only one evaluation tool for both the pre- and post-tests.

The evaluation tools were constructed according to the learner objectives of the education program. These objectives were based on the needs identified in the literature for parents of infants discharged home on supplemental oxygen (Glassanos, 1980; Pinney & Cotton, 1976; Srokosz, 1983; Young et al., 1988).

The objectives included information in the areas of physical characteristics of the infant, bronchopulmonary dysplasia and the need for supplemental oxygen, when to contact the physician, oxygen delivery systems, their use and safety precautions, the choking infant, cardiopulmonary resuscitation, family needs, resources in the community, the purpose for medications and how to give medications. Questions were developed with the intent that they should evaluate whether or not the program objectives were attained.

Construction of the tools also involved clinical experts and a parent group, all of whom were familiar with premature infants and the information needed to take such infants home. The evaluation tools were presented as multiple choice questions, with only one answer for each (Appendix B). One or two questions were included for each pertinent learner objective. Both evaluation tools were pilot tested for reliability and validity.

Reliability and validity

The tests for reliability include those related to stability, internal consistency, and equivalence. To establish stability measurement tools are administered once, and after a waiting period, are administered again to the same groups. The scores are then compared and a reliability coefficient (correlation coefficient) is determined (Polit & Hungler, 1983). The Pearson product moment correlation coefficient is used: $r = \Sigma(x-\bar{x})(y-\bar{y})/\sqrt{(x-\bar{x})^2(y-\bar{y})^2}$ (Ryan, Joiner, & Ryan, 1985). Reliability coefficients of 0.70 or greater are generally acceptable (Polit & Hungler, 1983).

One method used to establish internal consistency is the split-half technique (Polit & Hungler, 1983). The items comprising a measurement tool are split into two groups, even and odd numbered items. These items are then scored and the odd numbered items are used with the even numbered items to calculate a correlation coefficient. The Pearson product moment correlation coefficient is again used. However, since this calculation often underestimates the internal consistency of a tool, the Spearman-Brown prophecy formula is also used. This formula adjusts

the correlation coefficient to represent the reliability for the entire measurement tool. The Spearman-Brown prophecy formula is: $r = 2r/1+r$.

Equivalence is determined by administering two similar measurement tools to the same individuals at approximately the same time. The correlation coefficient is then calculated to obtain a measure of equivalence between the tools (Polit & Hungler, 1983).

Validity was determined by assessing content and "construct" validity. Content validity is based on judgement (Polit & Hungler, 1983) and can be confirmed by the use of experts in the topic area.

"Construct" validity is determined by whether or not the measurement tools actually measure what they are intended to measure. The known-groups technique is one method of establishing "construct" validity (Polit & Hungler, 1983). Groups are chosen that differ on the critical attribute. One group has the critical attribute while the other does not. Therefore, differences in scores should occur between the two groups. To establish a significant difference between group scores a one-tailed t-test for differences between means is utilized (Weinberg and Schumaker, 1974). The formula utilized was: $t = (\bar{x}_1 - \bar{x}_2)/\sqrt{s_1^2/n_1 + s_2^2/n_2}$ (Ryan, Joiner & Ryan, 1985).

Pilot project for reliability and validity

Reliability and validity were initially established for the evaluation of knowledge tools through pilot testing. Two samples of parents were used in this study. The first was a group consisting of parents who had an infant at home on

supplemental oxygen previous to or during the study period. The number of participants in this group was 24, or 12 families in which both parents responded. There were 12 mothers and 12 fathers. The second group consisted of parents who had no previous experience with an infant at home on supplemental oxygen, oxygen therapy, or neonatal intensive care. The number of participants in this group equalled 23. There were ten families where both parents responded, one family where only the mother responded and two mothers in single-parent families. There were 10 fathers and 13 mothers who participated.

The parents of infants who had been at home on oxygen were referred to as the group with knowledge (the group with the critical attribute). This group was obtained through the Foothills Hospital Neonatal Intensive Care Unit. The parents with no supplemental oxygen experience were referred to as the group without knowledge (the group without the critical attribute). This group was recruited through a private family practice from booked appointments on one randomly selected day. All parents were living in Calgary.

The questionnaires were delivered individually to each family and were collected within two to three days. After all the evaluation tools were collected the results were compiled into tables for both groups.

The two groups were obtained through different and restricted methods. As a result, it was necessary to determine whether or not the two groups were similar. In order to do this data were collected on parent age, parent education, age and number of children. To assess for a significant difference between means for these parameters two-tailed t-tests were utilized (Weinberg & Schumaker, 1974). The

formula was: $t = (\bar{x}_1 - \bar{x}_2)/\sqrt{s_1^2/n_1 + s_2^2/n_2}$ (Ryan, Joiner & Ryan, 1985). Based on the analysis of the information obtained it was determined that the two groups were similar with respect to parent education, age and number of children. The with knowledge group was found to be slightly older than the without knowledge group.

The evaluation tools were considered to be stable (reliable) over time. The correlation between the initial and delayed scores for tool number one was 0.70. The correlation between the initial and delayed scores for tool number two was also 0.70.

Internal consistency was indicated for both tools by reliability coefficients of 0.81 and 0.70 for tools one and two respectively. Equivalence was established by a correlation coefficient for tools one and two of 0.94.

Content validity was addressed by having the evaluation tools reviewed for appropriate content coverage by a clinical nurse, specialist, parent support group ("Beginnings") from the neonatal intensive care unit, neonatologists and a physician specializing in pediatric pulmonary medicine. Each item was also constructed according to a specific objective for knowledge acquisition developed for the education program.

"Construct" validity was indicated for both tools. A significant difference in scores between the group with knowledge and the group without knowledge was found for both tool one and tool two. The analyses of the pilot study data supported the reliability and validity of the evaluation tools for the chosen groups.

Demographic information. The evaluation tools were used to obtain demographic information from parents. The information collected included parent

age, sex, education (highest level attained), number of living children, ages of children and previous experience with home oxygen. The Blishen Index was used to identify the socioeconomic class of caregivers. The Blishen Index is an occupational prestige index of socioeconomic class in Canada (Blishen & McRoberts, 1976).

Evaluation of the education program. The program evaluation checklists were developed in order to obtain parent feedback on the program content and the methods of presenting the information (Appendix C). One evaluation checklist was constructed based on the learner objectives in order to determine to what degree parents felt the objectives had been attained. The other checklist was developed to ask parents how useful they found each portion of the program (booklet, videotape, practical session). Information from these checklists was descriptive.

Satisfaction with parenting scale. The Satisfaction With Parenting Scale was a previously developed questionnaire that scores Degree of Pleasure in the Infant and Parental Role Satisfaction on subscales. Totalled, the subscales comprise the Satisfaction With Parenting Scale (Ragozin et al., 1982). This scale includes 19 questions of which only 12 are actually utilized to obtain the score for each participant. Questions include the number of professionals the parent could talk to about the child, feelings about the child, the number of people the parent could talk to about problems with the child, feelings about child care and household chores, and time away from child care and household responsibilities. The questionnaire also asks how satisfied parents are with their answers to the above questions. The Satisfaction With Parenting Scale was previously used with mothers (Crnic,

Greenberg, Ragozin, Robinson, & Basham, 1983; Ragozin et al., 1982). Fathers also completed the Satisfaction With Parenting Scale. Reliability for this scale had been previously established (Ragozin et al., 1982). The higher the score for each individual, the greater the degree of satisfaction, with the lowest score being zero and the highest being 50. This information was used as a descriptive characteristic for the study subjects.

Data collection

Within one week of the decision to send an infant home on oxygen the parents were approached to schedule routine discharge teaching and to provide them with the opportunity to participate in the study. This initial contact was made by the head nurse. An attempt was made to schedule the teaching sessions in the same manner for all parents one to two weeks before the planned discharge date. Cardiopulmonary resuscitation was taught on the first day. The second day was the presentation of the education program for this study. Over the next week the parents met with the oxygen company who would supply their oxygen, and with representatives from the Infant Home Monitoring Clinic, Alberta Children's Hospital to discuss follow-up procedures. An attempt was also made to have all parents room-in with the infant for two nights. Routine baby care instruction occurred throughout. Single parents were encouraged to bring in a relative or friend to learn the information also.

The purpose of the study was explained to parents at the beginning of the education program, as well as what was expected of them during their participation.

They were then asked to sign a consent form (Appendix D) if they desired to be included in the study. If the parents agreed to participate, they were randomly given either evaluation of knowledge tool one or two to complete (the pre-test). After completion of the pre-test, parents were asked to work through the information booklet and were free to ask any questions that arose during that time. The booklet was followed by the videotape which reinforced information from the booklet and presented some new information. Time for questions or discussion was offered after viewing the videotape. The final component for the program was the "hands-on" experience. The investigator gave the parents an information sheet briefly listing what to consciously assess for their infant and equipment until they went home. The parents and investigator then worked through the information sheet with the infant, providing a demonstration, as well as an opportunity for the parents to return the demonstration. The program consistently followed the same sequences and was presented only by the investigator for all parents.

Following the "hands-on" session the parents completed evaluation of knowledge tool one or two (the post-test) depending on which had been administered as the pre-test. They also completed the program evaluation checklist. Four to six weeks after the actual discharge date of the infant (contingent upon parent availability), parents were contacted by telephone to schedule a follow-up visit. If parents were out of town, the telephone contact informed them that the follow-up questionnaires would be arriving by mail, and clarified what information was required from them. The delayed post-test (evaluation of knowlege tool) and a satisfaction with parenting questionnaire were administered at that time. At this

time parents were thanked for their participation. A thank you letter was also mailed to parents and offered them information regarding the study results if they were interested (Appendix E).

Analyses of results

Initially, the data were compiled into tables constructed of means, frequencies, standard deviations, ranges and possible ranges (where applicable). These tables allowed initial identification of trends and data requiring further exploration, and a description of the study group. Following this the t-test for differences between matched groups was applied to the pre-, post- and delayed post-test scores to answer the research question. The t-test was appropriate since it deals with differences in subject performance by the same subject under two conditions (Weinberg & Schumaker, 1974). A one-tailed t-test was used since the research question indicated directionality. When testing for differences between males and females a two-tailed t-test for differences between group means was used to assess for any differences between groups.

Correlation was used to identify the direction and strength of any linear relationships between the descriptive factors measured and the test scores. This was to help identify factors that may have influenced any changes in the test scores identified. Further analysis included simple, multiple and stepwise regression to identify any significant factors explaining variance in the test scores. Regression was considered an appropriate method for this analysis since it can be utilized with nominal, ordinal or interval data (Kleinbaum & Kupper, 1978).

Limitations of the study

1. The one group pre-test/post-test design imposed some restrictions on the interpretation of the study results regarding the delayed post-test. Delayed post-test scores could have been altered due to maturation, administration of the previous tests, history and regression toward the mean of the delayed post-test scores. Further, this design did not use a control group. Therefore the assumption that the education program was the variable influencing test scores was more difficult to make, due to the impact of other variables which may have been uncontrolled and/or not recognized.
2. The sample size was limited by the availability of subjects. The small sample size made it more difficult to have significant statistical findings and to generalize the findings to a larger population. The small sample size also increased the possibility of a Type II error (Burns & Grove, 1987).
3. The sample was obtained only from Foothills Hospital Neonatal Intensive Care Unit in order to minimize confounding variables from other hospitals. However, occasionally infants are also discharged home on supplemental oxygen from three other hospitals in this city. As a result, the sample may not be truly representative of the total geographic population of parents of infants discharged home on supplemental oxygen. The education program effectiveness could have been influenced by factors specific to Foothills Hospital and its neonatal intensive care unit, and so may not have indicated effectiveness in other hospitals.

Due to the above limitations the generalizability of the study results was limited. The factors imposing limitations included:

1. Sample size.
2. Sample source.
3. Environment and practices of the sample source.
4. One group pre-test/post-test design without a control group.

CHAPTER 4

Results

The results obtained from the quantitative data analyses are presented and summarized in this chapter. A descriptive analysis including means, standard deviations and ranges is presented first. This is followed by statistical analyses using t-tests and regression.

Family characteristics

Information describing the characteristics of caregivers included parent age, parent education, parent occupation, number of previous premature infants, number of living children, place of residence (urban or rural), and previous experience with oxygen therapy.

Ten women and eight men responded to all questions asked. The caregiver characteristics are shown in Tables 1 and 2. Family composition varied in the sample with one single parent (mother) family and one family composed of mother, father and grandmother as primary caregivers. Seven families were composed of mother and father all of whom participated in the study.

Table 1

Characteristics of Caregivers of Infants Discharged Home on Supplemental Oxygen

	N	Mean	Standard Deviation	Range	Possible Range
Age (years)	18	31.0	6.59	17.0-41.0	N/A
Education[a] (ranked)	18	2.778	1.263	1.0-4.0	1.0-4.0
Blishen Index (Blishen & McRoberts, 1976)	15	50.94	12.91	23.02-66.70	<30.0-70.0+
Satisfaction with Parenting Score[b]	18	38.11	4.74	28.0-45.0	0-50.0
Rural Home	8	N/A	N/A	N/A	N/A
Urban Home	10	N/A	N/A	N/A	N/A

[a]Education was ranked. See Table 2.
[b]Scores were obtained 4-6 weeks post-discharge.

Table 2

Frequency of Educational Ranks for Caregivers

Rank	No. of Caregivers/Rank
1 = < grade 12	4
2 = grade 12	1
3 = post-secondary or < Bachelor Degree	5
4 = Bachelor Degree	8
	n = 18

Parental age ranged from 17 to 41, with the range for mothers being 19 to 40 and for fathers from 17 to 41. The highest level of schooling reached was a Bachelor Degree. Four mothers and four fathers reached this level. The least amount of education obtained occurred for one mother and one father both of whom were enrolled in remedial school.The Blishen Index of occupational prestige, used as a measure of socioeconomic class (Blishen & McRoberts, 1976), indicated that on average caregivers were in the middle class. Ten parents were living in the city and eight parents were living in rural areas.

Six families had more than one living child with the maximum number being three. Two families had previously had a premature infant and two mothers had previous experience with oxygen. One mother had visited a relative on home oxygen therapy but had no experience with the operation of equipment or the caregiving. The other mother was a nurse and had experience with supplemental oxygen in the hospital setting. The Satisfaction With Parenting Scale was administered to 18 parents and overall gave an impression of family satisfaction with having the infant at home, cared for by the family. The items in Tables 1 and 2 were also assessed for differences between males and females. Analysis using the t-test for differences between group means indicated that there was no significant difference between males and females.

Infant characteristics

Ten infants were discharged home from Foothills Hospital Neonatal Intensive Care Unit on supplemental oxygen between May 1988 and May 1989, to nine

families. During the data collection period there were 719 infants admitted to the neonatal intensive care unit of which there were 214 ventilated survivors. The infants discharged home on oxygen were 1.39 percent of the total number of infants admitted, and 4.67 percent of the ventilated survivors. There was one set of twins both of whom were discharged home on supplemental oxygen. One infant was also a twin whose sibling had been discharged without oxygen prior to his discharge.

The information collected for infant characteristics included birth weight, discharge weight, gestational age, discharge age, discharge oxygen concentration, number of ventilator days, admission diagnoses, and discharge problems. These characteristics are illustrated in Table 3 or are discussed below.

Infant birth weight varied with gestational age and ranged from 600 grams to 3300 grams while gestational age ranged from 24 to 36 weeks. All infants received assisted ventilation with the number of days ranging from seven to 91. Discharge weight ranged from 2280 grams to 3280 grams and discharge age ranged from 38 days to 131 days. The discharge oxygen concentration ranged from 0.03 to 0.81 litres/minute.

Admission diagnoses included nine infants with hyaline membrane disease as the primary, initial diagnosis. Additional diagnoses for these nine infants included possible sepsis, patent ductus arteriosus and birth asphyxia. The tenth infant had non-immune hydrops fetalis with pleural effusions and lung hypoplasia. Characteristics at discharge included both diagnoses and required therapies. Diagnoses included retinopathy of prematurity and anemia. One infant was discharged home with hydrocephalus, one with hernias and one with multiple

Table 3

Characteristics of Infants Discharged Home on Supplemental Oxygen

	N	Mean	Standard Deviation	Range
Birth Weight (g)	10	1399	779	600-3300
Gestation (weeks)	10	29.60	3.50	24-36
Ventilator Days (days)	10	24.90	25.68	6-91
Discharge Age (days)	10	86.30	28.93	38-131
Discharge Oxygen Concentration (litres/minute)	10	0.275	0.2909	0.03-0.81
Discharge Weight (grams)	10	2739	275.7	2280-3280

hemangiomas. The therapies needed included supplemental oxygen and medications such as theophylline, hydrochlorothiazide, spironolactone and phenobarb. One infant was discharged home with an apnea monitor and one infant required a neurology follow-up and a retest for hearing. The characteristic similar for each infant was the discharge on supplemental oxygen. At discharge seven of the ten infants also had one or more of the other medical problems or therapies discussed above.

Evaluation of knowledge scores

Table 4 contains a description of the parents' scores on the evaluation of knowledge tools for the pre-test, post-test and delayed post-test time periods. The sample means were 14.38, 17.33 and 17.17, respectively.

Table 4

Pre-Test, Post-Test and Delayed Post-Test Characteristics

	N	Mean	Standard Deviation	Range of Possible Scores	Range of Obtained Scores	Correl'n with Post-Test Scores	Correl'n w/ Delayed Post Test Scores
Pre-test Scores	18	14.38	3.72	0-24	6-21	0.701	0.670
Post-test Scores	18	17.33	3.91	0-24	8-23	-	0.810
Delayed Post-test Scores	18	17.17	4.41	0-24	9-24	0.810	-

Table 5 illustrates a significant difference between the scores of the knowledge tests as obtained by t-tests. A one-tailed t-test was utilized to determine the significance of the difference between pre-test and post-test scores since the hypothesis to be tested was that post-test scores would be higher than pre-test scores. The alpha level was 0.05. A one-tailed test was also used to test the difference between the delayed post-test scores and the pre-test scores, to establish if the delayed post-test scores were again greater than the pre-test scores. The alpha

Table 5

Differences Obtained Between Test Scores

	Post-Test Scores	Delayed Post-Test Scores
Pre-Test Scores	t = 4.22[a] p = 0.0003	t = 3.51[a] p = 0.0013
Post-Test Scores	- -	t = -0.27[b] p = 0.79

[a]One-tailed test. H_1: Post-test scores > Pre-test scores; H_2: Post-test scores = Pre-test scores. α=0.05.
[b]Two-tailed test. H_1: Delayed post-test scores ≠ post-test scores; H_2: Delayed post-test scores = post-test scores. α=0.05.

level was 0.05. A two-tailed test was used to test for any difference between the post-test and delayed post-test scores. The alpha level was 0.05. Each test was scored out of 24. All parents answered all questions and all tests were returned.

Table 6 illustrates the frequency of the knowledge scores for all three tests and Tables 4 and 7 contain descriptions and correlations of the pre-test, post-test and delayed post-test scores. The pre-test will be discussed first. All parents responded to the questions. The minimum and maximum scores were six and 21 respectively. The highest correlation of the pre-test with the caregiver/infant characteristics was 0.552 and was with parent education. The next most highly correlated variable was parent age, r = 0.479. Regression was used to assess the significance of the effect of these factors on the pre-test scores (Table 8). With an alpha of 0.05 there were two significant variables identified with simple regression:

Table 6

Frequency of Knowledge Scores Obtained for Caregivers

		Number of Caregivers/Range		
		Pre-Test	Post-Test	Delayed Post-Test
Range of Scores	0 - 2	0	0	0
	3 - 5	0	0	0
	6 - 8	1	1	0
	9 - 11	3	1	3
	12 - 14	5	0	2
	15 - 17	6	7	3
	18 - 20	2	6	7
	21 - 23	1	3	2
	24	0	0	1

Table 7

Test Score Correlations with Other Factors

	Pre-Test Scores	Post-Test Scores	Delayed Post-Test Scores
Birth Weight (grams)	0.102	0.235	0.194
Discharge Weight (grams)	-0.358	-0.296	-0.207
Gestation (weeks)	0.145	0.222	0.137
Number of Ventilator Days	0.204	0.317	0.454
Discharge Oxygen Concentration (litres/minute)	0.370	0.539	0.572
Discharge Age (days)	-0.174	-0.168	-0.011
Blishen Index	0.125	0.124	0.436
Caregiver Age (years)	0.479	0.668	0.553
Caregiver Education (rank)	0.552	0.536	0.594

Table 8

Significant Predictors of Pre-Test, Post-Test and Delayed Post-Test Scores

	Simple Regression[a]			Stepwise Regression[b]	
	r value	t value	R^2 value	t value	R^2 value
Pre-Test Scores:					
Caregiver Age	0.479	2.38	22.9%	-	-
Caregiver Education	0.552	2.89	30.5%	-	-
Post-Test Scores:					
Caregiver Age	0.668	3.92	44.7%	-	-
Caregiver Education	0.536	2.77	28.8%	-	-
Discharge Oxygen Concentration	0.539	2.79	29.0%	-	-
Delayed Post-Test Scores:					
Caregiver Age	0.553	2.89	30.5%	-	-
Caregiver Education	0.594	3.22	35.2%	-	-
Discharge Oxygen Concentration	0.572	3.04	32.7%	-	-
Number of Ventilator Days	0.454	2.22	20.6%	3.37	46.94%
Gestation	0.137	-	-	2.20	46.94%

Note. Tests were two-tailed.

[a]Degrees of freedom = 16, α=0.05 using simple regression with individual variables.
[b]Degrees of freedom = 15, α=0.05 using stepwise regression with both variables in the equation.

caregiver age and education. Multiple regression did not yield significant variables, nor did stepwise regression.

Post-test information is shown in Table 4. All parents responded to all questions. The minimum and maximum scores were eight and 23 respectively. The highest correlations (Table 7) of the post-test with family variables were with caregiver age, discharge oxygen concentration and caregiver education respectively. Regression was used to identify any significant predictors of post-test scores. Three variables were identified as significant by simple regression, as identified in Table 8. These were again caregiver age, discharge oxygen concentration and caregiver education. No variables were identified as significant by either multiple or stepwise regression.

The delayed post-test scores are summarized in Table 4. The minimum and maximum scores were nine and 24 respectively. The caregiver/infant characteristics most highly correlated with the delayed post-test scores were caregiver education, discharge oxygen concentration, and caregiver age as illustrated in Table 7. Regression was used to determine which, if any, of the family/infant characteristics explained variance in the delayed post-test scores. As indicated in Table 8 the four variables that were significant with simple regression were discharge oxygen concentration, caregiver age and education and the number of ventilator days. The significant variables in stepwise regression were gestation and the number of ventilator days. Together they explained 46.94% of the variance in the delayed post-test scores.

Evaluation of the education program

An evaluation of the education program was completed by subjects. The program objectives were evaluated on a scale from fully completed to not completed. All parents felt that greater than 50 percent of the objectives were fully obtained by the end of the education program (Table 9). Fifty percent of parents felt that greater than 80 percent of the objectives were fully obtained. The evaluation of knowledge tools (tests) were also assessed item-by-item to identify if any post-test questions were consistently answered incorrectly. There were 2 questions found that were consistently incorrect. Both dealt with components of cardiopulmonary resuscitation.

Table 9

Parents' Perceptions of Objectives Fully Completed

Parents (n=18) (%)	Objectives Fully Completed (%)
38.8	100
5.5	90
11.1	81.8
16.6	72.7
16.6	63.6
11.1	54.5

Parents were also asked to complete an evaluation of the education program components (Table 10). This evaluation allowed parents to rate the usefulness of the program components (booklet, videotape, practical session) on a scale from very useful to not useful. None of the caregivers found any one component of the

program to be not useful with 100 percent finding the practical session to be very useful.

Table 10

Parents' Perception of Usefulness of Program Components

	Very Useful (% of parents)	Somewhat Useful (% of parents)	Not Useful (% of parents)
Booklet	94.4	5.6	0.0
Videotape	66.7	33.3	0.0
Practical Session	100	0.0	0.0

CHAPTER 5

Summary, Conclusions and Implications

Summary

There was one major objective in this study. This was to evaluate the impact of an education program on parental/caregiver knowledge. The group chosen was that of caregivers of infants discharged home on supplemental oxygen. As a result it was necessary to design and produce an education program specifically for these caregivers.

The program was developed according to principles of adult learning and was based on identified needs (as discussed in the literature) for this group of caregivers. The study sample was comprised of 18 caregivers of infants discharged home on supplemental oxygen over a period of one year. This group included both mothers and fathers, and in one instance a grandmother as a primary caregiver.

A one-group pre-test/post-test study design was used and the data were collected only by the researcher, using evaluation tools developed for the study. The evaluation tools were pilot tested prior to the initiation of the study to establish reliability and validity.

Study information was gathered at the time of the discharge teaching and six-weeks post-discharge. All education programs followed the same format.

Conclusions

Research question: Is the education program effective for increasing knowledge of caregivers?

This question was addressed by the completion of t-tests for significant differences between pre-test, post-test and delayed post-test scores. The data analyses indicated that there was a significant difference between the pre-test and post-test, and pre-test and delayed post-test scores. In both cases the post-test scores were significantly higher than the pre-test scores.

Discussion of the results

Evaluation of knowledge. The significant difference found between the pre-test and post-test scores could be considered to be due to the education program itself. The tests were administered as follows. The pre-test was completed immediately prior to the presentation of the program and the post-test was completed immediately following the program. There were no interruptions during any of the teaching sessions which may have influenced the scores. As a result the effects of history and maturation would have been minimal. The pre-test and post-tests were different evaluation tools, which were similar in construction and content. Therefore, the effect of administration of the pre-test on post-test scores cannot be ruled out. Most parents verbally identified the questions they did not know answers to during the pre-test and actively sought the information during the education session. It is highly probable therefore, that the higher post-test scores were the

result of the education program since other events were eliminated and most parents actively sought information.

There was a significant difference between the pre-test scores and the delayed post-test scores. The delayed post-test scores were higher. However, this result may not have been due to the education program. The delayed post-test was not administered until six weeks post-discharge and therefore was subject to the effects of maturation, administration of the two previous tests, and history. For some families influencing factors included rehospitalization of the infant, as well as visits to the Infant Home Monitoring Clinic with or without a subsequent decrease in the amount of supplemental oxygen required by the infant. As a result of events other than the education program, which may have occurred between administration of the pre-test and delayed post-test no firm conclusions may be drawn regarding the impact of the program on retention of knowledge. However, since the post-test and delayed post-test scores are very close (no significant difference was found), the delayed post-test scores may have been the result of the lingering effects of the education program.

For the reasons discussed above it is also difficult to draw conclusions regarding the effectiveness of the education program for retention of knowledge when comparing the post-test and delayed post-test scores. There was no significant difference identified for the post-test and delayed post-test scores. The delayed knowledge levels measured may have been due to the education program although other factors may have had an influencing role.

The pre-test scores had a standard deviation of 3.73 with a range from 6 to 21 (the total possible score was 24). Due to the large range found, pre-test scores were analyzed using both caregiver and infant characteristics. These included parent age, education and occupation, infant birth weight, gestation, discharge weight, discharge age, discharge oxygen concentration and the number of ventilator days. Discharge oxygen concentration roughly reflects the extent of lung disease present at discharge and the number of ventilator days may reflect the degree of illness in each infant. Higher values in both characteristics represent a greater degree of lung disease and illness respectively. Discharge age may partially reflect the extent of illness and/or the degree of lung disease present, as may birth weight. Parent education may be a reflection of reading skills and the ability to integrate and/or utilize the information given.

When the above characteristics were used to try to explain the variation in pre-test scores the highest correlations were $r = 0.552$ with parent education, and parent age, $r = 0.479$. However, when simple, multiple and stepwise regression were utilized to examine the variance in pre-test scores none of the characteristics were identified as significant predictors of scores. This indicates that there are other factors which influenced the pre-test scores which were not identified in this study. It may also indicate that the method of scoring education, or other characteristics, was not precise enough to identify their impact as significant. Other factors which might be considered include parental stress, including not only family sources but external sources, social support and individual personality characteristics including

coping mechanisms and previous experience with crisis or anxiety producing situations.

The same characteristics were used to examine the variation in post-test scores. The standard deviation was 3.91 with a range in scores from eight to 23. The highest correlation found between the infant/caregiver characteristics and the post-test scores were $r = 0.668$ with parent age, $r = 0.539$ with discharge oxygen concentration, and $r = 0.536$ with parent education. When simple, multiple and stepwise regression were completed there were no significant predictors of post-test scores identified.

Parent age may be useful in predicting scores due to its effect on experience. It is possible that the older the parent the more experiences that are available for reference and so learning of the practical or most relevant information becomes easier. It is also possible that the range of reference is wider in older parents and so may contribute to the acquisition of needed knowledge. Perception of the importance of the information presented to parents may also vary with age and/or experience. When caregiver scores were assessed there was no pattern evident in the age of those caregivers who did not increase their scores on the post-test. The same was true of those who did increase their scores. When those who scored low (less than 12) on the pre-test were separated out, those who did not increase their scores were younger than the other subjects. It was not evident that the older the subject the larger the increase in score. As a result, it is difficult to recognize age as a predictor of post-test scores since it was also highly correlated with pre-test scores. It is possible that other undetected factors influenced the post-test scores.

Discharge oxygen concentration may have been useful in predicting post-test scores as it is one indication of the extent of lung disease present in the infant. As discharge oxygen concentrations increased, generally the severity of lung disease increased. It may be that the degree of illness in the infant may influence the degree to which parents perceive information regarding the infant as important. Parents may have more concerns for the infant using higher supplemental oxygen concentrations and so may be more motivated to learn.

Parent education was also identified as a predictor of post-test scores using simple regression. As with the pre-test it is possible that with a more detailed description of the educational level of parents its importance would have altered its importance as a predictor. If education is a reflection of reading skills of parents it is possible that the post-test scores were influenced by education since one portion of the program was printed material (the booklet). When assessed for readability the level of education required for using the booklet was evaluated as grade nine. When caregiver scores were assessed there was no pattern evident in the education of those caregivers who did not increase their scores on the post-test. This was again true of those who did increase their scores. However, when those with low (less than 12) pre-test scores were separated out, those who did not increase their scores had the lowest level of education (enrolled in remedial school). No other patterns were observed. Some of the information in the booklet is also presented in either the videotape, practical session or both. As a result it is possible that the learning that did occur took place using skills other than reading. However, it is

difficult to recognize education as a valuable predictor of post-test scores since it was also highly correlated with pre-test scores.

Consideration must also be given to caregiver characteristics that were not measured in this study which may influence post-test scores. As with the pre-test these include parental stress including internal, family and external sources, social support, and individual personality characteristics. One further influencing factor may have been the amount of time parents took to work through the booklet.

The chosen caregiver and infant characteristics were again used to try to explain the variation in delayed post-test scores. The standard deviation for these scores was 4.41. The range for the scores was from nine to 24. The characteristics most highly correlated with the scores were parent education, $r = 0.594$, discharge oxygen concentration, $r = 0.572$, parent age, $r = 0.553$, and ventilator days, $r = 0.454$. These factors were also significant predictors of delayed post-test scores when assessed using simple regression. However, when stepwise regression was used the only significant predictors were gestation ($r = 0.137$) and the number of ventilator days.

As previously discussed the number of ventilator days and gestation may have reflected the course of the infant during hospitalization and the extent of lung disease at discharge. This in turn may have influenced parental perceptions and so their need for knowledge regarding their infants. It may be that the more prolonged the initial hospital treatments and the greater the lung disease at discharge the greater the perceived vulnerability of, or risk for, the infant going home. It is possible that this perception increases the need for knowledge. These predictors

may indicate the degree of wellness after discharge. If infants of lower gestation who require longer periods of assisted ventilation, are less well post-discharge, or parents perceive them as less well, knowledge may be retained for longer periods of time or parents may continue to seek more information.

The variation in delayed post-test scores could have been subject to factors not assessed in this study. These other factors could include readmissions to hospital, experiences with the infant and/or oxygen equipment, family support and functioning as well as other factors including anxiety and stress.

Evaluation of the education program. All parents indicated that the one-to-one teaching was the most valuable component of the program. This component included the practical session as well as the time allowed for parents to ask any questions and discuss any areas of concern. The preference for the practical session may have been due to its flexibility with regard to time. Parents were able to spend as much time as needed asking questions and working with their own infant. Learning was also reinforced during this time as parents demonstrated skills or asked questions and were given immediate feedback. The videotape provided no opportunities for demonstration and information was presented continuously. Parents did not often interrupt the videotape and so may have lost opportunities to ask questions. The booklet was the second most preferred component of the program. Parents were able to ask questions as they arose even though the booklet contained most of the information they required. The ability to ask questions throughout may have made both the booklet and practical session

more helpful formats for learning than the videotape. The practical session was the most flexible of the presentation formats.

Some parents indicated that not all of the program objectives were met. This supports the need for ongoing education for the parents by staff nurses in addition to the program. It may be helpful in the future to continue to assess which objectives are consistently not met. It would then be possible to modify the education program to emphasize the information, or to ensure the staff nurses provided information regarding those objectives.

The objective that was most commonly only partially met for parents in this study was regarding the administration of oral medications. Six of eighteen parents indicated this objective was partially met. One parent felt this objective was not achieved at all. The most common comment by these parents was that they needed to learn how to actually draw-up medications. This is addressed by routine discharge teaching by the staff nurses. However, upon review, the program booklet and/or practical session could include this component.

Five of eighteen parents indicated that the objective regarding knowledge of bronchopulmonary dysplasia (BPD) was only partially met. This information is covered in the program booklet but learning may be facilitated by a brief discussion of BPD, its etiology and treatment after caregivers have finished the reading.

The post-test questions were reviewed individually to identify whether there were any questions that were consistently answered incorrectly. This was done to facilitate the identification of objectives not fully met.

Two questions indicated a lack of knowledge of cardiopulmonary resuscitation (CPR). This area was not indicated by parents as not being fully addressed by the program. However, one question asked parents to order the importance of the steps involved in initiating CPR. Sixteen out of 18 respondents completed this question incorrectly. This suggests that parents may benefit by further review or teaching of cardiopulmonary resuscitation. CPR learning might benefit from more practice time after the initial teaching is completed.

A related question regarding the action to take with a choking infant was the question that was the next most often answered incorrectly. Ten of 18 parents incorrectly answered this question. This further indicates the necessity for either more or different cardiopulmonary resuscitation instruction. An increase in "hands-on" participation may enhance learning.

Implications of the findings

1. The information obtained from this study indicates that the education program did increase parental knowledge as assessed immediately after the program. Structured consistent education programs should be used for caregiver education.
2. An observation made throughout the study was the usefulness of the pre-test for parental learning. It gave parents an indication of what they did and did not know. Most parents used that information to direct their questions and learning from the program content. As a result it may be beneficial to continue to utilize the pre-test as a part of the education program. Overall

parents expressed pleasure at the availability and content of the program.

3. Reference material should be given to parents to take home as most parents indicated they would be reading through the booklet again before the infant was discharged.
4. Parents with limited reading skills may require further instruction utilizing practical, verbal and/or audiovisual methods.
5. Evaluation of how well objectives are met and program component usefulness should be ongoing so the program remains relevant and facilitates parental learning.
6. Education program review should occur at least once each year so the information (phone numbers, CPR standards) can be updated.
7. The education program should not be implemented as a self-study program. Parents consistently asked questions throughout. A resource person should be available to answer questions.

Suggestions for further research

1. A case-control study using a larger sample could provide more information regarding the effectiveness of the education program and the impact of other factors. This study could include more detailed variables such as parental stress, education in years, the amount of time required to complete the booklet, and retention of knowledge.
2. A more detailed investigation using the satisfaction with parenting scores may be useful. When an analysis of the differences between male and

female scores was done there was no significant difference even though mothers tended to do more of the household and child care tasks and tended to have fewer social contacts and time to themselves. However, the numbers for comparison were too small to draw any conclusions (males n = 8, females n = 10).

3. A study utilizing more qualitative information may be useful. Both nurse and parent perceptions of the benefits and/or limitations of the program would provide valuable information.

4. A study comparing different program formats could be done to provide information regarding the most useful modes of teaching for families with special needs infants.

5. The study could be replicated with an earlier follow-up of the family. Within two weeks of the discharge home, caregivers could provide information about the education program. This information could include what helped them the most initially, which component was the most helpful, and why.

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APPENDIX A

Education Program

The education program was developed following several steps which were:

1. The purpose of the program was defined as "to assist parents of infants being discharged home on supplemental oxygen in the adjustment to, and coping with, the infant at home through increasing their knowledge."
2. The area of content was defined as: (a) information regarding infants who are discharged home on supplemental oxygen due to bronchopulmonary dysplasia; (b) the etiology and treatment of bronchopulmonary dysplasia including the rationale for treatment; (c) oxygen equipment and safety issues with home oxygen therapy; (d) cardiopulmonary resuscitation; (e) medications; and (f) parent care/coping at home.
3. The description of parents or the audience was the next step. This was essential to establish an education program that met the needs of the participants. The parents were those whose infant was being discharged home on supplemental oxygen because of bronchopulmonary dysplasia. Motivation was assumed to be high.
4. The level of knowledge required before taking the program was determined. It was determined that individuals would require both basic knowledge regarding premature infants, and neonatal intensive care experience in the parent role. This level of knowledge was necessary to avoid including

information in the program which did not directly pertain to home oxygen therapy for infants with bronchopulmonary dysplasia.

5. What participants should be able to do at the end of the program was defined. In this program the participants should have been able to meet the objectives established for the program and so demonstrate an increase in knowledge.

Other considerations that were important before developing the program included establishment of the relevance of the topic. It had to meet the needs of the audience. It was also important to assess the demand for the education program including the number of participants expected to benefit, whether there was another program previously established that was available, how the needs of the participants had previously been met and was this sufficient? Further, it was important to assess the addition of this program to current teaching. For this education program it was decided that current teaching would continue and the program would be used as a supplement to that teaching.

Lesson plan

Objectives. The learner objectives were established according to identified learning needs from the literature and were as follows:

The learner will be able to:

1. Describe the physical characteristics of the infant.
2. Explain bronchopulmonary dysplasia.
3. Explain the need for oxygen for growth and development.

4. Identify signs of and implications for an increase in oxygen need.
5. Identify problems with the infant indicating the need to contact the physician.
6. Identify the major parts of oxygen delivery systems.
7. State essential procedures when using liquid oxygen in the home.
8. State safety precautions when using oxygen.
9. State the basic steps for helping a choking infant.
10. State the basic principles of cardiopulmonary resuscitation.
11. Identify potential family needs.
12. Identify resources for meeting family needs.
13. State what medications the infant requires.
14. State the purpose for the medications.
15. State how to give medications.

Learning principles and teaching strategies. These concepts (see text, pp. 20, 21, 36, 37) were taken into acount as the education program formats were chosen so they could be constructed to facilitate learning.

Content and evaluation tools. These components were developed based on the program objectives. Each objective is represented in the booklet, the evaluation of knowledge tools (Appendix B) and the program evaluation checklists (Appendix C). There were two evaluation of knowledge tools developed so that participants did not fill out the same tool for both the pre- and post-test. The content and wording of the education program and the evaluation of knowledge tools were assessed by experts after each draft was completed until agreement was

reached regarding the content, wording, and clarity of these components.

The education program was composed of three parts. The booklet contained the greatest amount of information and detail since parents were able to take this information home as a reference. The videotape reinforced some information from the booklet. One such area was infant characteristics which emphasized the respiratory system. The second area of review was cardiopulmonary resuscitation. These two areas were considered essential learning and so were chosen for reinforcement. The third area of content in the videotape was home oxygen therapy in practice. This section introduced parents visually to the equipment and procedures for home oxygen therapy as well as reinforced safety precautions.

Finally, the practical session with parents reinforced the infant respiratory characteristics and included a very basic introduction to flow metres and oxygen tubing.

Three formats for presentation were chosen to take into account different learning styles and principles of adult learning. For the program content, see the next pages.

Infants
Going Home in Oxygen

Information for Parents

Foothills Hospital

Table of Contents

Acknowledgements

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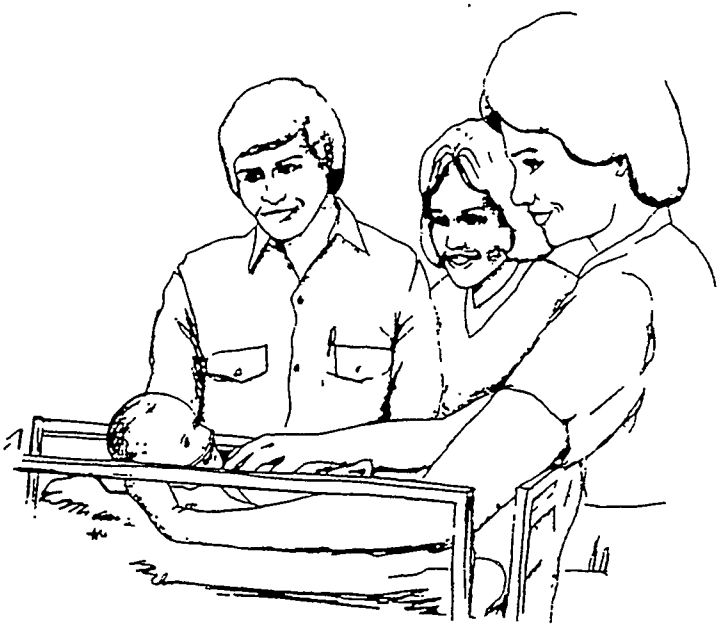
Introduction

The purpose of this booklet is to help you feel more comfortable with taking your baby home in oxygen.

The objectives of this booklet are:

1. To provide you with an easy reference for information you need.
2. To increase your knowledge about your baby and oxygen therapy.
3. To decrease your anxiety about taking your baby home in oxygen.

This booklet is set up to encourage self-learning. Following each different section there are some questions with room for you to provide your answers. If you wish to check your answers, the correct answers are provided in the text of the section preceding the questions and at the back of the booklet. Answering the questions should reinforce the information that is necessary for you to take your baby home in oxygen.



I. Bronchopulmonary Dysplasia

A. What is Bronchopulmonary Dysplasia (BPD)?

BPD is a long-term lung disease that typically affects an infant who was premature, has been on a ventilator and has received extra oxygen. If the infant needs assisted ventilation for a long period of time, lung damage is common.

BPD is thought to be caused by repeated injury and healing in the lungs. The injury is caused by the oxygen delivered under pressure to the lungs over a long period of time. If you could see the lungs of an infant with BPD you would see areas of scarring.

B. How is BPD treated?

BPD is treated by oxygen therapy, the use of medications such as lasix and/or theophylline, maintenance of good nutrition and vigorous treatment of respiratory infections.

C. Why oxygen?

Your baby's injured lungs cannot get enough oxygen in room air so he/she requires extra oxygen. Oxygen is needed so the **heart, brain and lungs** can grow and develop normally.

If your baby does not have enough oxygen in the blood the heart must work harder. With too little oxygen the blood vessels leading to the lungs become narrow so the heart must work harder to get blood to the lungs. Since the heart is working hard the muscle in the right side of the heart may get thicker and the right side of the heart may enlarge. This causes the heart to work less effectively and become weak (heart failure). Heart failure may occur slowly or suddenly and must be treated medically.

It is important that your infant always receives his or her oxygen so the strain on the heart can be minimized.

D. How long will my baby be in oxygen? 87

Your baby **will get better slowly** because the lungs needs time to heal and grow. Generally, babies no longer need the extra oxygen by **6 - 11 months of age.** Most babies outgrow the symptoms of BPD.

Can you now recall?

1. What is BPD? _____
   _____
2. What is thought to cause BPD?_____
   _____
3. Why is extra oxygen needed? _____
   _____
4. What major organs require oxygen to grow and develop normally?
   _____, _____, and _____.

II. Oxygen Equipment

A. What equipment will we have at home?

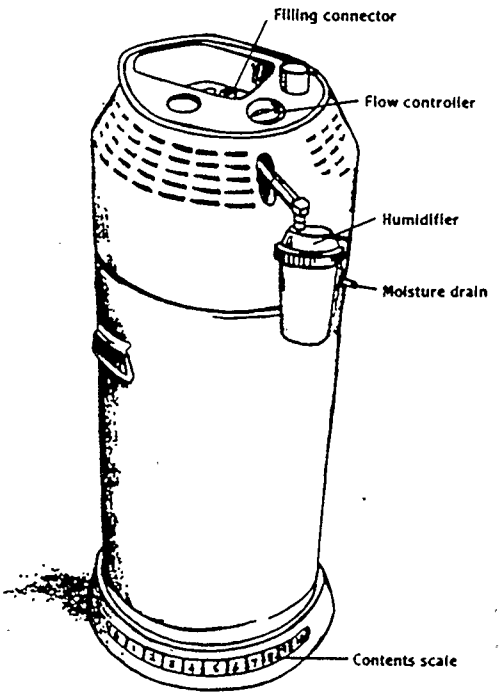
You will have **2 pieces** of equipment at home. These are:

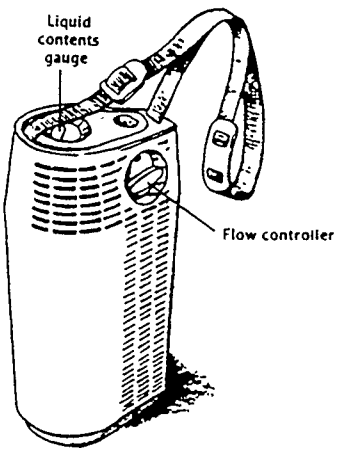
1. A large oxygen tank.
2. A smaller, portable oxygen tank.

The large oxygen tank has **4** parts:

1. A **flow meter** to adjust the amount of oxygen delivered to your baby.
2. A **measuring gauge** showing the amount of oxygen left in the tank.
3. A **humidifier** attachment.
4. **Connector tubing** with nasal prongs. (Also obtained from your oxygen supplier.)

The small tank has 3 parts. They are the same as the large tank **except** there is no humidifier. If you do require a humidifier for the small tank you can discuss this with your oxygen company representative. Humidification is usually not necessary for the short periods your baby uses the portable tank.





B. How often do the oxygen tanks need to be filled?

The length of time between filling the tanks varies depending on how much oxygen your baby is in. As a rough guide, the **large tank** needs to be filled about **once (1) per week.** You will **fill the small tank yourself from the large one** when the measuring gauge indicates that it is low.

C. How much oxygen does my baby need?

Initially, the hospital will tell you how much oxygen your baby needs. Leave your baby on that amount **except** for situations of distress or if your baby looks dusky.

You will be going to the **Infant Home Monitoring Clinic** at the Alberta Children's Hospital. At regular intervals you will have your baby's oxygen needs assessed on an oxygen saturation monitor. The clinic will want to monitor the baby during feeding and sleep. This makes sure your baby is getting enough oxygen and provides opportunities to decrease your baby's oxygen.

D. What must I do?

1. Check oxygen flow rate every **2** hours (except during the night).
2. Check tank pressures every **4** hours (except during the night). Make sure you check both flow rate and tank pressure before going to bed and when/if you get up for night feedings.
3. Check to see that the nasal prongs are properly aligned on baby's face.
4. To ensure the prongs are clean and not blocked, check them daily.
5. Change the prongs when unclean or every **2** weeks.
6. Change the **distilled water** in the humidifier bottle every **2** days.
7. Wash the humidifier bottle with vinegar and soapy water once each week.
8. Change the humidifier bottle every **3** weeks.

E. What Safety Precautions must I be aware of?

1. Liquid oxygen is **very cold**. Be careful when working with valves and filling the small tank.
2. The mechanisms may freeze when you are filling the small tank because the oxygen is so cold. If this happens leave the small tank in place on the large one and allow the fittings to warm up. Then proceed as usual.
3. Tanks must be kept **upright** because the oxygen is liquid. In the car hang the portable tank by the shoulder strap around the headrest of the front seat so it will swing freely. This avoids the possibility of the tank tipping over.

Because oxygen make things burn faster:

4. Post **no smoking** signs in your house and enforce them.
5. Keep tanks at least **6 feet** from lighted fireplaces.
6. Keep an all purpose **fire-extinguisher** available and visible.
7. Store tanks in a cool, dry, well-ventilated area.
8. Do **not** use vaseline or baby oil on your baby.

For problems with nasal prongs:

9. Keep extra prongs available in case of a blockage in the prongs being used. (i.e.: if baby vomits)
10. You may want to take one connector tubing with nasal prongs and cut off the end with the prongs above the point where the tubing splits. (Discard the prongs.) Keep this tubing with the tank you are using. If the baby's prongs become plugged in some way you can still blow oxygen into your baby's face by attaching the cut tubing to the tank. Then you can prepare new prongs for your baby.

Do your remember?

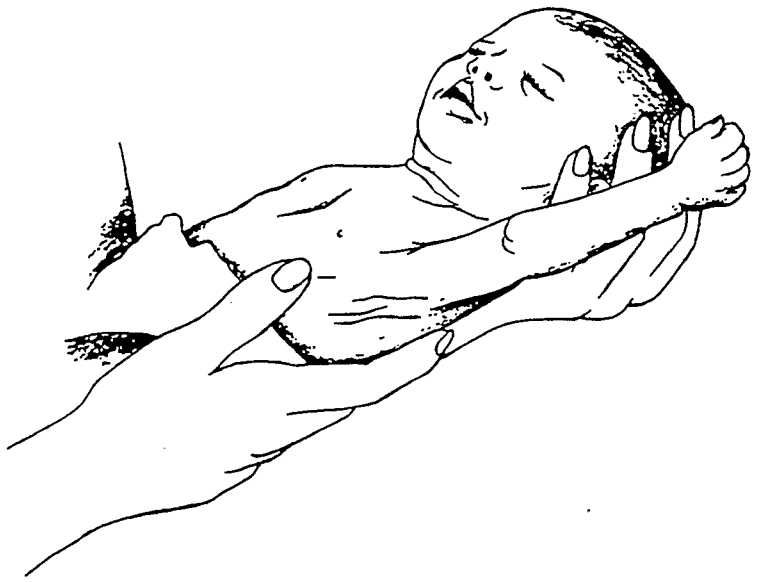
1. Keep oxygen away from _____
2. Do not use _____ or _____ on your baby's skin.
3. In what position should you keep the oxygen tanks? _____
   _____
4. The temperature of liquid oxygen is very _____
5. Smoking should be allowed. Yes or no? _____
6. Keep a _____ handy and visible.

III. Your Baby

A. What should my baby look like

Your baby should breathe at a rate of **40 - 60 breaths per minute**. Your baby may have some **indrawing** (illustration below).

Your baby should be **pink all over** especially the lips and nailbeds on his or her hands and feet. The area around the mouth should be pink and your baby's breathing should be relaxed and easy. Some indrawing may be normal for your baby. You need to be familiar with your baby's normal chest movement.



B. What are the Warning Signs of Distress?[92]

1. An **increased breathing rate** over more than 1 hour where there are more than 60 breaths per minute.
2. An **increased effort** when breathing, such as more indrawing than usual or nasal flaring, may indicate that your baby is in distress.
3. Other signs include:
   (a) **Duskiness,** which is a bluish tinge to nailbeds and lips and may be obvious other places.
   (b) Your baby may be **irritable** and/or very **tired and inactive.**
   (c) Your baby may make **unusual sounds** such as **wheezing** when he or she breathes or your baby may have a **cough.**

Can you recall?

1. How fast should your baby normally breathe? _____
2. Where are the first places to look for duskiness?
   _____ and _____.
3. What are the 2 signs of distress?
   1. _____ 2. _____.
4. What are 2 signs of increased breathing efforts?
   1. _____. 2. _____.

C. What should I do if my baby has warning signs of distress?

1. Look for any **blockage of oxygen flow** to your baby.
   Things to **check** include:
   (a) **the prongs**
   - Are they blocked?
   - Are they in your baby's nose?
   - Are they attached to the tank being used?
   - Is baby's nose clean and clear?

   (b) **the tank**
   - Is the tank on?
   - is the tank empty?
   - Is the tank upright?

2. Increase your baby's oxygen flow.
   - Duskiness should go away within 10 - 15 minutes.
   - Your baby's effort to breathe should decrease.
   - Your baby's breathing rate should slow down.

Note:

If your baby's breathing does not improve **or** if your baby has unusually noisy respirations or difficulty breathing call and go to your doctor or **Alberta Children's Hospital Emergency** as soon as possible.

Question:

In what order would you do things if baby became dusky?

_____a) increase oxygen to baby
_____b) check prongs to ensure in nostrils
_____c) call hospital if no improvement
_____d) settle baby
_____e) check connector tubing attachments and see if tank is on

D. How can I tell if my baby is becoming ill?[94]

If you think your baby is becoming ill with a cold or flu ask yourself these questions: .

1. Are my baby's body, face, lips and/or nailbeds blue?
2. Is she/he working harder to breathe and/or breathing much faster than usual?
3. Is he/she wheezing more and/or coughing frequently?
4. Is he/she refusing to eat or eating much less than usual?
5. Is he/she vomiting most of the day's feedings?
6. Does he/she have less than five wet diapers in 24 hours?
7. Is his/her axilla temperature greater than 37.5 C?
8. Is his/her activity level greatly increased or decreased?
9. Is he/she sleeping much more or less than usual
10. Are his/her hands, feet or eyes puffy?

If you answer yes to any of these questions phone your family doctor or pediatrician. It is common for babies and children with BPD to be readmitted to the hospital if they become ill.

E. What are some helpful tips for you?

- Baby is more likely to be very sick with a cold. It is a good idea to avoid visits with people who have colds.
- Keep a close eye on baby if he or she catches a cold. Watch for signs of difficulty breathing or lack of oxygen. He/she may need more oxygen during this time.
- Baby powder can irritate the respiratory tract and should not be used. .
- Smoke, cigarette smoke, dust and/or plant pollens may trigger wheezing or coughing.
- Lying baby on stomach may help to make breathing easier.
- Settle baby as quickly as possible. Prevent irritability.

IV. Choking Baby and Cardiopulmonary Resuscitation

A. What do I need to know about a choking baby?

If your baby is choking he or she may be gasping, gagging or coughing and may turn blue.

If baby can clear his/her airway alone he/she will do so fairly quickly.

If your baby is more than a few seconds trying to clear his/her airway then you must help.

1. Hold your baby on your lap.
2. Turn him/her over onto his/her stomach, head lower than feet.
3. Give 4 back blows between the shoulder blades with the flat palm of your hand.

4. Turn baby over on your lap and give 4 chest thrusts with 2 fingers at the nipple line.
5. Check to see if you can see something in baby's mouth. If you can see something do a finger sweep and remove it. If you cannot see anything do **not** do a finger sweep but try to breathe into baby's lungs. If air goes into baby's lungs he/she may have swallowed the object instead of spitting it out.
6. If air does not go in repeat steps 1 to 6 until you get results.
7. Check to see if baby is breathing. Rate 40 - 60 per minute. Baby's colour should improve. If **not** go to step 8.
8. If baby is **not** breathing start artificial breathing (mouth to mouth) **Call 911** and then continue breathing until baby starts breathing on own or until help arrives.
9. If baby is breathing observe him/her for the next ½ to 1 hour watching for breathing rate, effort and colour.

B. What do I need to know about Cardiopulmonary Resuscitation

If baby does not appear to be breathing:

1. See if baby responds to shaking and shouting
2. See if baby is breathing

- **LOOK** at chest for movement
- **LISTEN** for breathing
- **FEEL** for breath from nose

C.P.R. (continued)

3. If baby is **not breathing:**

AIRWAY
- ensure neck area not restricted
- neck not extended or hyperextended
- try 1 quick puff of air through baby's nose and mouth
- reposition head and try 1 quick puff again
- if air won't go in do back blows and chest thrusts as for choking baby
- if baby is not breathing repeat puffs of air, if baby is breathing continue with back blows.

BREATHING
- when air goes into lungs stop after 2 puffs and check for pulse on inner elbow. Make sure you check for a count to 10. There is usually a pulse.
- call 911

CIRCULATION
- if there is a pulse continue with artificial breathing until help arrives or baby starts breathing on own
- if there is no pulse start CPR and continue until help arrives.

Recall:

1. How to see if baby responds? _____ and _____.
2. Steps to check for breathing? _____, _____ and _____.
3. If not breathing you would _____ and then _____.

V. Medication Your Baby May Receive[98]

A. How should I give Medications

If your baby is on medications they should be given with a little formula or expressed breast milk.

If your baby vomits the feed you gave the medications with **do not** give the medications again. Just give the next dose at the proper time.

It is helpful to keep a schedule posted to mark off when you have given the medications. (see page 21 and 22).

Draw up the night medications before going to bed so you will not have to be measuring them in the middle of the night.

Medications may include:

1. **Vitamins** - Polyvisol, Vitamin E
2. **Iron** - Fer-in-sol
3. **Bronchodilators** - Theophylline
4. **Diuretics** - Lasix, Hydrochlorothiazide, Spironolactone (or Aldactazide)

B. What do the medications do for my baby?

Vitamins and **Iron** will help your baby's growth and development.

Theophylline (a bronchodilator) opens up the air passages making breathing easier for baby.

Lasix, Hydrochlorothiazide and **Spironolactone** (or Aldactazide) help your baby get rid of water from the lungs which otherwise could make it difficult for your baby to breathe.

Questions:

1. What should you **not** do if baby vomits the feed with the medications?

_____

2. What medications is your baby on? _____

_____

3. Do you recall what the medications are for? _____

_____

VI. Caring for Yourself or Coping at Home

A. What About Me?

This section deals with you, your family and friends.

As a parent you need **time-off** both alone and with your husband or wife. This means you will need **babysitting resources**. Find a friend or relative who is willing to learn to care for your baby and teach them. You can get assistance for childcare but you must apply early. Processing of applications takes time. For more information phone Handicapped Children's Services at 297-2248. If you need help around the house or if you need a babysitter you can phone the Calgary Family Service Bureau at 228-2130. Fees are charged on a sliding scale based on income.

You do need to see to your own needs. Some tips are:

- Make an effort to **spoil yourself** once each day. (Both parents need to do this).
- **Do** take advantage of friends and/or family who will babysit. You **do** need time out!
- **Do** go out with friends and/or family. You need social interaction with other **adults**.
- **Do** talk with friends and/or family about concerns or problems. If you would like to talk with someone who has experienced taking home an infant who was premature you can call Louise Piechotta of "Beginnings" at 275-0447.

B. What about my other children

100

Your other children need time with you alone and time with you and their new baby. You can try to arrange this around your baby's sleep times.

You will continue to need babysitting for your other children as well as your new baby.

C. What about getting out with my baby?

You can get out of the house!

A portable oxygen tank will be delivered to your home. It is light enough to carry over the shoulder or to hang on a stroller.

You and your baby will both benefit from being out occassionally.

Apply for a handicap parking sticker. You are eligible because your baby is using oxygen. For more information on obtaining a sticker call 297-4210 (Motor Vehicles Division).

If you want or need to travel long distances you can. For information contact the airline you will travel with.

D. What can I do to keep my baby happy?

It is important for premature babies to have periods of uninterupted sleep so they can grow and develop. It is also important to have time for interaction with the family.

The best time to intereact with your baby is when he/she is well rested, usually before or after a feeding. The best place is in a quiet and not too brigthly lit room. At first, most babies prefer face-to-face interaction with their parents and brothers/sisters. These periods will also be short at first. Try not to overwhelm your baby with a great many toys.

Premature babies tend to become overstimulated easily. Watching your baby's responses to stimulation will alert you to when this is happening. Premature babies most often respond to overstimulation by becoming irritable.

Leaving your baby "alone" does not mean unsupervised.

When your baby is spending "alone" time he or she may be in the same room with you or you may frequently check on him or her if he or she is in another room.

E. What can I do when my baby is upset?

When your baby becomes upset and out-of-control try any of the following:

1. Wrap the baby snuggly in a soft blanket.
2. Turn on a "white" noise like a vacuum, hair dryer or humidifier.
3. Let your baby suck.
4. Place your baby in his or her favorite position.
5. Play soothing music.
6. After your baby is calm try leaving him or her alone for a while (decrease stimulation).
7. Try rocking, walking or a car ride with your baby.

F. When will my baby begin to show changes in behaviour?

Your baby will become more responsive and social with time but changes may be slow. **Do not rush** your baby. He or she will set the pace for interactions.

Do not compare your baby to a baby born at term (40 weeks). Your baby had a different beginning from a term baby and will develop differently. There is nothing wrong with your baby developing slowly. Your baby will generally "catch-up" to other children by age three.

> Not every day will be a perfect, happy day. Except to have some bad days and do not get discouraged. Your baby will grow up because **you are a good parent!**

Reference Book

Sammons, W. and Lewis J. *Premature Babies a Different Beginning*, Missouri: The C.V. Mosby Company, 1985, pp. 136-151, 200-221.

Names and Telephone Numbers [103]

	Name	Number
Baby's Doctor:	_____	_____
Oxygen Company:	_____	_____
Community Health Nurse:	_____	_____
Respiratory Therapist:	_____	_____
Infant Home Monitoring Clinic: (Alberta Children's Hospital)	_____	_____
Close Friend, Relative or Babysitter:	_____	_____
Alberta Children's Hospital Emergency:	_____	_____
Ambulance:		911
Support Group - "Beginnings":	Louise Plechotta	275-0447

Notes

Medications Chart

Medication/Dose	Time	Date						
		Mon	Tues	Wed	Thurs	Fri	Sat	Sun

Medications Chart

Medication/Dose	Time	Date						
		Mon	Tues	Wed	Thurs	Fri	Sat	Sun

Answers to Questions

I **Bronchopulmonary Dysplasia** (page2)

1. What is BPD? **BPD is a long-term lung disease requiring oxygen therapy.**
2. What is thought to cause BPD? **Long-term ventilation and extra oxygen.**
3. Why is extra oxygen needed? **In room air baby's injured lungs cannot get enough oxygen.**
4. What major organs require oxygen to grow and develop normally? **Lungs, heart,** and **brain.**

II. **Oxygen Equipment** (page4)

1. Keep oxygen away from **lighted fireplaces.**
2. Do not use **baby oil** or **vaseline** on your baby's skin.
3. In what position should you keep the oxygen tanks? **In an upright position. In a well-ventilated area.**
4. The temperature of liquid oxygen is very **cold.**
5. Smoking should be allowed. Yes or no? **No**
6. Keep a **fire extinguisher** handy and visible.

III. **Your Baby** (page7)

1. How fast should your baby normally breathe? **40 - 60 breaths per minute.**
2. Where are the first places to look for duskiness? **Lips** and **nailbeds.**
3. What are 2 signs of distress?
   1. **Irritability** 2. **Duskiness** Others: **Tired and inactive, cough, wheezing or other unusual noises.**
4. What are 2 signs of increased breathing effort?
   1. **Nasal flaring** 2. **Increased indrawing**

In what order would you do things if baby became dusky? (page9)

b	a)	increase oxygen to baby
e	b)	check prongs to ensure in nostrils
a	c)	call hospital if no improvement
d	d)	settle baby
c	e)	check on connector tubing attachments and see if tank is on

Answers (continued)

IV. **Cardiopulmonary Resuscitation (CPR)** (page12)

Recall:

How to see if baby responds? **shake** and **shout**
Steps to check for breathing? **look, listen** and **feel**
if not breathing you would call 911 and **start CPR**

V. **Medications** (page 14)

1. What should you **not** do if baby vomits the feed with the medications? **You should not give the medications again. Give when the next dose would usually be due.**
2. What medications is your baby on? **List medications your baby is taking.**
3. Do you recall what the medications are for? **Vitamins and iron will help your baby grow. Theophylline opens up the air passages making breathing easier for your baby. Lasix, Hydrochlorothiazide and Spironolactone help your baby get rid of water from the lungs which otherwise could make it difficult for your baby to breathe.**

Foothills Hospital is southern Alberta's main teaching and referral health care centre. Providing acute and auxiliary care programs to residents of northwest Calgary. Foothills also provides a range of specialized services to southern Alberta, including neonatal care, renal dialysis and transplantation, diabetes clinics and a burn unit. All southern Albertans benefit from the unique coordination of Foothills Hospital, the University of Calgary Faculty of Medicine, the Tom Baker Cancer Centre and the Provincial Laboratories, all located on the Foothills Medical Centre site.

Voluntary contributions to support the work of the Hospital are encouraged through the Foothills Hospital Foundation. For further information, please contact the Foundation offices at 270-1932.

PREPARED BY THE DEPARTMENT OF NURSING
PRODUCED BY EDUCATIONAL RESOURCES
FOOTHILLS HOSPITAL 88/04 (B2149)

Script for Parent Education Videotape

Infants born prematurely may require an extended period of assisted ventilation and increased oxygen. As a result of prolonged intubation, oxygen and other factors, the lungs of the infant are often damaged. The most frequent type of damage is called bronchopulmonary dysplasia or BPD. Because of BPD the infant may require an extended period of oxygen therapy after extubation.

Introduction

The purpose of this videotape is to review and reinforce information useful for the parents of infants who are discharged home on oxygen.

The areas of focus in this videotape will be: (a) the infant's size and respiratory characteristics; (b) cardiopulmonary resuscitation or CPR; and (c) oxygen equipment. The discussion will include safety precautions and useful tips for caring for the equipment.

The infant

First, we will talk bout the effort it takes for your baby to breathe. Typically, infants who are discharged home on oxygen were premature. As a result, they are smaller than infants born at term when they go home.

Normally, the baby should breathe at a rate between 40 and 60 per minute. Chest movement should be easy. Baby should not look like he or she is working hard. A baby who is working hard will show you signs of increased respiratory

effort. One such sign is indrawing, as on this infant. You may see the small spaces between the ribs indraw also as the baby works to breathe. The next time you look at your baby notice the chest movement.

Another sign of increased effort when breathing is nasal flaring. Normally, baby's nostrils will stay in the same position when breathing. If baby is having difficulty breathing nostrils may flare out when breathing in and return to normal when breathing out.

Next we will talk about how to tell if baby is not getting enough oxygen. Normally, baby should be pink all over. If he or she is not getting enough oxygen signs will first show up in the nailbeds. The nailbeds will have a bluish colour. The lips will also look blue if baby is not receiving enough oxygen. The area around the mouth and nose may also look blue. This bluish colour is called cyanosis or duskiness.

Other signs of not enough oxygen include a baby that is lethargic, irritable or restless. An increased breathing rate that stays high may also indicate a breathing problem.

If baby experiences any of these things, first check the oxygen equipment. Check to see that the tank is on and the tubing attached. Make sure there are no kinks in the tubing and that prongs are in baby's nose and are not blocked. If everything is all right and baby is still dusky, increase oxygen slightly. Duskiness should slowly go away. Then reduce oxygen again. If problems continue, you should contact your physician.

That sums up the section on the infant respiratory characteristics.

C.P.R.

The next section deals with CPR and the choking infant. First we will look at what to do for the choking infant.

If your baby chokes he or she may be dusky and either gagging or coughing. If baby does not stop shortly and cannot get the object out you must help. First check baby's mouth for foreign objects. If you can see something there, tilt baby's head down and remove the object with a finger sweep. Do not attempt to scoop object out with a finger if you cannot see it as this may push it farther down. Make sure baby is still breathing.

If you cannot see anything in baby's mouth, hold baby's face down, head tilted down and give four back blows. Turn baby over and give four chest thrusts. Then check baby's mouth for object. If you can see the object, remove it with a finger sweep. If it is not there, try to breathe into baby's lungs. If air does not go in, repeat back blows and chest thrusts. If air goes in, baby may have swallowed the object instead of spitting it out. Make sure baby is breathing by listening for air passage, looking for chest movement and feeling for breath on your cheek. The steps to remember are face down, head down, four back blows, four chest thrusts.

If baby is not breathing, call for help - dial 911. You do have the time to spare. Then make sure the head is positioned properly. This is called ensuring a clear AIRWAY. Attempt to put in puffs of air - BREATHING. Next check for pulse on baby's arm - CIRCULATION. You must check the pulse for a good 10 seconds. There usually is one. If there is no pulse, begin cardiac compressions:

five compressions to one breath. The sequence is fairly fast. Continue until medical help arrives.

The key words are LOOK, LISTEN and FEEL. Remember A-airway, B-breathing and C-circulation.

Home on Oxygen

The final section of this videotape will deal with oxygen equipment. This equipment may not look exactly like yours but all the parts you will have to deal with are basically the same.

First, we will look at the large, stationary tank. Most families place this tank close to the baby's crib in a corner of the room. It will have a contents scale that indicates the amount of liquid oxygen left in the tank. The respiratory company will tell you when you should call to have more oxygen brought.

The large tank will have a humidifier attachment. The large tank will also have a flow meter to adjust the amount of oxygen baby receives. Leave baby on the amount of oxygen determined by the hospital initially and then by the Infant Home Monitoring Clinic.

The other part of the tank to consider is the filling port for the small tank. This small tank is portable and is filled from the big one.

The portable tank has the same parts as the large tank. There is a contents scale and flow meter. The only thing that is different is the absence of the humidifier bottle. For the short periods of time the baby uses the portable tank, a humidifier is not necessary. If it is essential that baby has humidification that can

be arranged by the respiratory company.

Two cautions: (1) liquid oxygen is very cold - do not touch any frosted parts or connections; and (2) keep tanks upright to avoid spillage of contents.

Further safety tips include:

1. No smoking in the house.
2. Keep oxygen 5 to 6 feet away from lighted fireplaces or open flame.
3. Do not use baby oil or vaseline on baby.
4. Keep a fire extinguisher available.
5. Keep tanks upright.
6. Store tanks in a cool, well ventilated area.

Finally, for day-to-day problems or routine care of your infant, contact either the community health nurse or your family doctor. If you have problems or concerns with the oxygen equipment or respiratory status of your infant, contact either the respiratory equipment supply personnel or physicians and staff at Alberta Children's Hospital, particularly the Infant Home Monitoring Clinic.

"Hands-On" for Parents of Infants Discharged Home on Oxygen

For the next few times you are with your infant in the N.I.C.U. look at your infant undressed.

Observe
- the chest shape and size
- the amount of chest movement with breathing
- the number of breaths per minute
- count the number of breaths per minute
- find the baby's pulse on the inner side of the elbow

Observe
- the colour of your baby
- the lips and nailbeds (lips and nailbeds should be pink)

Observe
- the nasal prongs
  - cleanliness
  - position
  - taping

Observe
- baby's activity
- what makes baby calm down
- what makes baby cry

Observe
- the flow meter being used for your baby. This is what your flow meter will look like
- the humidification bottle. This is what your humidity bottle will look like.
- the tubing attached to the humidification bottle. Look for kinks or blockages. Make sure it is attached to the oxygen outlet.

APPENDIX B

Evaluation of Knowledge

Tool # 1

Please circle the best response for the following questions.

Please circle only one response for each question.

Please put a star by any questions that are unclear or difficult to understand.

1. Baby should normally breathe at a rate of:

   a) 80-100 per minute

   b) 20-30 per minute

   c) 30-50 per minute

   d) 40-60 per minute

2. Cyanosis is:

   a) a bluish colour indicating baby is not getting enough oxygen

   b) a term referring to a pale baby

   c) a shade of pink used when talking about baby

   d) a term indicating too little oxygen

3. An infant who is premature typically:

   a) is the same size as term newborns of the same age

   b) has a flexible rib cage that may move obviously with breathing

   c) has an inflexible rib cage with no obvious movement with breathing

   d) is big for his or her age

4. Indrawing is:

    a) a noise baby makes when breathing

    b) arm movements baby makes when crying

    c) obvious chest movement in, when baby breathes in

    d) a noise baby makes when crying

5. Bronchopulmonary dysplasia is a term which means:

    a) difficulty breathing

    b) a disease requiring a ventilator for long-term treatment

    c) a long-term lung disease

    d) a type of cold a baby may catch

6. Bronchopulmonary dysplasia is thought to be caused by:

    a) high levels of oxygen which some babies require

    b) long-term ventilation

    c) prematurity

    d) extra oxygen, prematurity and long-term ventilation

7. Signs of the need for more oxygen may include:

    a) increase in activity and responsiveness

    b) cyanosis and irritability

    c) decreased rate of breathing

    d) a content baby

8. Body organs affected by lack of oxygen are:

    a) lungs and heart

    b) brain only

    c) lungs, heart and brain

    d) lungs only

9. Oxygen is necessary for:

    a) growth

    b) development of baby

    c) the lungs to heal

    d) all of the above

10. Safety precautions with oxygen include:

    a) no smoking

    b) not using vaseline or baby oil

    c) keeping tanks upright

    d) all of the above

11. The home oxygen system includes:

    a) a humidifier

    b) a gauge indicating amount of oxygen left for each tank

    c) oxygen flow meters and two tanks

    d) all of the above

12. Your baby needs:

    a) a lot of stimulation

    b) complete quiet to sleep

    c) a lot of undisturbed sleep

    d) to be left alone a lot

Is baby on medications? yes_____ no____

If yes, continue 13-15. If no, go to 16.

What are the medications?_____

13. Theophylline is for:

    a) opening baby's airways

    b) stimulating the heart

    c) stimulating baby's breathing

    d) helping baby get rid of extra water

14. Lasix or hydrochlorothiazide and spironolactone (or Aldactazide) are for:

    a) steadying the heart rate

    b) making breathing easier

    c) increasing the amount of water lost by baby

    d) all of the above

15. Give medications:

    a) with a little milk

    b) in the side of the mouth

    c) again if vomited with feeding

    d) all of the above

16. Please list in order of their importance the following steps for CPR (cardiopulmonary resuscitation)

a) shake and shout 1._____

b) call for help 2._____

c) check for pulse 3._____

d) start artificial breathing 4._____

e) start chest compressions 5._____

f) look, listen and feel for breathing 6._____

17. What would you do with a choking baby who could not clear his/her own airway?

a) start back blows and chest thrusts

b) start mouth-to-mouth breathing

c) turn him/her on the stomach, head down until he/she stops choking

d) all of the above

18. When using home oxygen it is a good idea to:

a) check flow rates, tubing and prongs, amount of oxygen left in tanks and baby's condition every 2-4 hours during the day

b) check all equipment day and night every 2 hours

c) check all equipment once each day in the morning

d) check flow rates, tubing and prongs, amount of oxygen left in tanks and baby's condition every 4 hours day and night

19. You should call your doctor if:

    a) baby's breathing rate stays above 80 per minute for more than 6 hours

    b) baby has a temperature above 37.5 degrees celsius

    c) eyes, hands or feet become more puffy than usual for your baby

    d) all of the above

(Evaluation tool #1 designed by author.)

Tool # 2

Please circle the best response for the following questions.

Please circle only one response for each question.

Please put a star by any questions that are unclear or difficult to understand.

1. Baby needs oxygen for which of the following:

   a) lungs to heal

   b) growth

   c) development

   d) all of the above

2. When a premature infant is ready to go home, baby typically:

   a) has a flexible rib cage that may move obviously with breathing

   b) is big for his/her age

   c) is the same size as term newborns of the same age

   d) has an inflexible rib cage with no obvious movement with breathing

3. When baby goes home he/she will need:

   a) complete quiet to sleep

   b) to be left alone a lot

   c) a lot of stimulation

   d) a lot of undisturbed sleep

4. When a baby is said to have some cyanosis this means:

   a) baby is pale

   b) baby is a bright pink colour

   c) baby is receiving too little oxygen

   d) baby is a bluish colour that indicates too little oxygen

5. The organs of the baby most affected by too little oxygen are:

   a) brain only

   b) lungs, heart and brain

   c) lungs only

   d) lungs and heart

6. Using home oxygen means checking things sometimes. Which of the following should you do?

   a) check all equipment once each day in the morning

   b) check flow rates, tubing and prongs, amount of oxygen left in tanks and baby's condition every 4 hours day and night

   c) check all equipment day and night every 2 hours

   d) check flow rates, tubing and prongs, amount of oxygen left in tanks and baby's condition every 2-4 hours during the day

7. When dealing with liquid oxygen certain safety procedures are important:

   a) keeping tanks upright

   b) no smoking

   c) not using vaseline or baby oil on baby

   d) all of the above

8. The breathing rate per minute for your baby should be:

   a) 20-30

   b) 80-100

   c) 40-60

   d) 30-50

9. When a baby is said to be indrawing it means:

   a) arm movements baby makes when crying

   b) a noise baby makes when crying

   c) a noise baby makes when breathing

   d) obvious chest movement in, when baby breathes in

10. Babies often choke. If your baby choked and could not clear his or her own throat what should you do?

   a) start mouth-to-mouth breathing

   b) turn him/her on the stomach, head down until he/she stops choking

   c) start back blows and chest thrusts

   d) all of the above

11. The term bronchopulmonary dysplasia refers to :

   a) a long-term lung disease

   b) difficulty breathing

   c) a type of cold a baby may catch

   d) a disease requiring a ventilator for long-term treatment

12. The equipment you will have at home to deliver oxygen includes:

    a) oxygen flow meters and two tanks

    b) a humidifier

    c) gauges indicating amount of oxygen left in tanks

    d) all of the above

13. It is thought that infants get bronchopulmonary dysplasia from:

    a) long-term ventilation

    b) prematurity

    c) high levels of oxygen which some babies require

    d) all of the above

14. Baby may show you if he/she needs more oxygen by:

    a) a decreased rate of breathing

    b) a content baby

    c) a increase in activity and responsiveness

    d) cyanosis and irritability

15. Most daily concerns can be handled by your community health nurse or clinic. However, you should know when to contact your physician. You would contact your doctor if:

    a) baby has a temperature above 37.5 degrees celsius

    b) baby's breathing rate stays above 80 per minute for more than 6 hours

    c) baby's eyes, hands or feet become more puffy than usual for your child

    d) all of the above

Is baby on medications? yes_____ no_____

If yes, continue 16-18. If no go to 19.

What are the medications?_____

16. To give medications to baby you should:

    a) give them again if vomited with the feeding

    b) give them in only a little bit of milk

    c) give them in the side of the mouth

    d) all of the above

17. Diuretics are medications given to babies with BPD. They are lasix or hydrochlorothiazide and spironolactone (or Aldactazide) and are for:

    a) increasing the amount of water lost by baby

    b) steadying the heart rate

    c) making breathing easier

    d) all of the above

18. What is the medication theophylline given to babies for?

    a) stimulating the heart

    b) helping baby get rid of extra water

    c) stimulating baby's breathing

    d) opening baby's airways

19. Please list in order of their importance the following steps for CPR (cardiopulmonary resuscitation):

a) shake and shout 1._____

b) call for help 2._____

c) check for pulse 3._____

d) start artificial breathing 4._____

e) start chest compressions 5._____

f) look, listen and feel for breathing 6._____

Comments or suggestions:

_____

_____

_____

_____

_____

_____

(Evaluation tool #2 designed by author.)

Please complete the following:

Sex: M_____ F_____

Age:_____

Education obtained: _____

Occupation:_____

Number of children:_____ Ages:_____

Previous experience with any type of oxygen in the home:

Yes_____ No_____

If yes, please describe:_____

_____

_____

_____

APPENDIX C

Evaluation Tool: Achievement of Learner Objectives

Please indicate the degree to which you feel that you can now achieve the following by placing a (✓) in the appropriate column. Please feel free to make comments.

Objective	ACHIEVED TO MY SATISFACTION	COULD HAVE BEEN MORE FULLY ACHIEVED	NOT ACHIEVED (EXPLAIN WHY)	Comments
1. Describe the physical characteristics of the infant.				
2. Explain BPD (broncho-pulmonary dysplasia), the cause and treatment.				
3. Explain the need for oxygen for growth and development.				
4. Identify signs of and implications for increasing the infant's oxygen.				
5. Identify the major parts of oxygen delivery systems.				
6. State safety precautions when using oxygen.				
7. State the basic principles of CPR.				
8. Identify potential family needs.				

Objective		ACHIEVED TO MY SATISFACTION	COULD HAVE BEEN MORE FULLY ACHIEVED	NOT ACHIEVED (EXPLAIN WHY)	Comments
9.	Identify resources to meet family needs.				
10.	State why infant is on medications.				
11.	State how to give medications.				

Evaluation Tool - Format

Please indicate the degree to which each teaching method was useful for you by placing a (✓) in the appropriate column.

Please feel free to make comments.		VERY USEFUL	SOMEWHAT USEFUL	NOT USEFUL (EXPLAIN WHY)	Comments
1.	I found the booklet to be:				
2.	I found the video to be:				
3.	I found the practical session to be:				

(Format for evaluation tools from:
Department of Adult Education and Division of Continuing Education in the Health Sciences. Program Planning Guide for Health Professionals, Vancouver: University of British Columbia, 1980.)

(Evaluation tools designed by author.)

APPENDIX D

Consent Form

Research Project: The evaluation of a parent education program for infants discharged home on oxygen.

Investigator: Krista Brown, B.N., R.N., Graduate Student, University of Calgary.

Dear _____:

This consent form is part of the process of informed consent. It should give you a general idea of what the research project is about and what your participation will involve. If you would like more information about the project, or information not included here, please ask. Please take the time to read this carefully.

The purpose of the research is to determine whether or not an education program is effective in increasing knowledge for parents of infants discharged home on oxygen.

The study will be done with parents of infants discharged home on oxygen. Parents will receive an education program including: written materials, a videotape and one-to-one teaching regarding physical care of the infant, behavioural styles and patterns of the infant and needs of the parents and family.

Information to be collected includes background information on the parents, a pre-, post- and delayed post-test for knowledge and a satisfaction with parenting score.

All information will be anonymous and kept strictly confidential. No names will be placed on the information collection sheets.

Parents will receive new and updated information about the research project by telephone. There is no financial cost to participants in the research. Medical treatment will not be influenced with or without participation in the project.

Your signature on this form indicates that you have understood the information regarding your participation in the research project. It also indicates agreement to participate as a subject. You are free to withdraw from the study at any time. Your continued participation should continue to be as informed as your initial consent. Please ask for clarification or new information whenever you have questions or concerns.

If you have questions, please contact:

Krista Brown, 239-5150 (or 270-1453)

Researcher Signature	(Name)
Date	(Signature of Subject)

(from: Informed Consent in Research Involving Human Experimentation, University of Calgary Conjoint Medical Ethics Committee, 1986.)

APPENDIX E

Thank You Letter

34-908 Ranchlands Blvd. N.W.
Calgary, Alberta
T3G 1X9

_____, 1989

Dear Mr. & Mrs. _____,

Thank you very much for participating in my research project: Evaluation of an Education Program for Parents of Infants Discharged Home on Oxygen. At this time I am continuing to include families in the study. I should complete the study by late spring. If you wish any information about the study please feel free to contact me at that time.

I hope you found the education program helpful and wish you the best with your family. Once again, thank you for your assistance.

Yours truly,

Krista A. Brown R.N., B.N.
Graduate Student
University of Calgary
Phone: 239-5150 or 270-1354