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Case studies : home care needs of ventilator dependent children with congenital central alveolar hypoventilation syndrome

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**Case studies: Home care needs of ventilator-dependent children
with congenital central alveolar hypoventilation syndrome**

Jackson, Davia LaVerne, M.S.

San Jose State University, 1990

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CASE STUDIES: HOME CARE NEEDS OF
VENTILATOR DEPENDENT CHILDREN
WITH CONGENITAL CENTRAL ALVEOLAR HYPOVENTILATION SYNDROME

A Thesis
Presented to
The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
Davia Jackson
December, 1990

ABSTRACT

CASE STUDIES: HOME CARE NEEDS OF VENTILATOR DEPENDENT CHILDREN WITH CONGENITAL CENTRAL ALVEOLAR HYPOVENTILATION SYNDROME

by Davia Jackson

The purpose of this study was to examine factors which impact families providing home care to ventilator dependent children, more specifically children with Congenital Central Hypoventilation Syndrome (CCHS). The nonrandom study sample consisted of two families providing home care in lieu of hospitalization to ventilator dependent children with CCHS. The narrative case presentations addressed five areas: (a) diagnosis, (b) hospital discharge, (c) home care and equipment, (d) psychosocial aspects, and (e) the developmental/medical status of the child.

Answers to the following questions were obtained:

(a) What are the benefits of ventilation at home? (b) What are the complications and disadvantages to home care? (c) What is the social, emotional, and financial impact of home ventilation on the family? Both families agreed that home care was a more humane approach to the care of medically stable ventilator dependent children. The data suggest that home ventilation can be disruptive to the family unit.

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To my family
Melvin, Stona, Khaliah, and Crystal
for your understanding
during a period of
contrasting interests and demands

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Chapter 1

INTRODUCTION

The detrimental effect of long term institutionalization on the development of children has been widely acknowledged in the past several decades (Burr, Guyer, Todres, Abrahams & Chiodo, 1983). The use of sophisticated medical technology has made it possible for increasing numbers of children to survive the acute effects of extreme prematurity, neurologic diseases, severe trauma, and congenital abnormalities (Burr et al., 1983). The history of the ventilator dependent child dates back to the 1940s and 1950s. Goldberg, Collen, and Monahan (1988) pointed out that the movement for home care of ventilator dependent patients began as a result of poliomyelitis epidemics 40 years ago.

According to Burr et al. (1983), home ventilator care for children abruptly came into national focus when President Reagan announced at a news conference in November 1981 that rules regarding eligibility for Supplementary Security Income (SSI) would be waived to allow Katie Beckett, a ventilator dependent child, to return home without losing Medicaid benefits. Subsequently, the Surgeon General held a two-day workshop entitled "Children with Handicaps and Their Families" (Burr et al., 1983), the objectives of which were to:

1. plan a systems approach to provide health care for ventilator dependent children and their families, and
2. develop strategies for organizing and providing this care in a cost-effective manner.

Reimbursement agencies are now considering changes in policies, and government authorities are making changes in legislation, most significantly at the state level, in order to augment consumer endeavors, in an effort to maintain ventilator dependent patients at home. This research study was conducted to investigate one group of ventilator dependent children, those with Congenital Central Alveolar Hypoventilation Syndrome (CCHS), in order to determine the impact of home care on the family.

CCHS, also known as Ondine's Curse, is a rare condition characterized by a marked depression of respiratory drive during sleep (Guilleminault et al., 1982). Ventilation is normal while the patient is awake. CCHS may lead to respiratory failure, corpulmonale, and death if untreated (Weesner & Boyle, 1985). The usual treatments for this condition include tracheostomy with long term mechanical ventilation.

Advances in the therapeutic modalities associated with long term management of patients with complicated respiratory problems have resulted in improved quality and quantity of life for these patients

(Kopacz & Moriarty-Wright, 1984; Schreiner, Donar, & Kettrick, 1987). No longer is the patient who is partially or totally dependent on mechanical ventilation a rarity. Increasingly, the complex needs of the patients are challenging the health care system, health care providers, and the lay community.

The Problem and Research Questions

There is minimal information available regarding the home care needs and associated problems and/or advantages of ventilator dependent children and more specifically children with CCHS. The intent of this study was to gather information from the experiences of individual families with children with CCHS, who brought their ventilator dependent children home from intensive care units. Inquiry into these cases focused on medical, social, and financial aspects. The study attempted to answer the following questions:

1. What are the benefits of ventilation at home?
2. What are the complications and disadvantages of home ventilation?
3. What is the social, emotional, and financial impact of home ventilation on the family?

Purpose and Need

The primary objective of home ventilation is to enable patients to leave the hospital. Decreased cost of care and

psychological benefits to families and patients are cited as advantages of home care with a ventilator dependent person (Splaingard, Frates, Harrison, Carter & Jefferson, 1983; Hazlett, 1989). The purpose of this study was to conduct an in-depth investigation regarding the home care management of families with ventilator dependent children with CCHS.

Definition of Terms

For the purposes of this study, the following definitions were used:

1. Congenital Central Hypoventilation Syndrome is a rare disorder involving abnormal central control of ventilation during sleep (Guilleminault et al., 1982). The long term evolution of this disorder is unresolved, and is commonly treated with a tracheostomy and mechanical ventilation during sleep.

2. Ventilation is the movement of air in and out of the lungs, which occurs normally with breathing. Mechanical ventilation occurs when an individual cannot breathe adequately on his/her own. The individual is connected to a ventilator machine, which assists and/or breathes for them.

3. Tracheostomy refers to an external airway into the trachea.

Research Design

This explanatory study investigated factors which impact families providing home care to ventilator dependent children, more specifically children with CCHS. A case-study approach was used to identify the advantages and disadvantages associated with home care of ventilator dependent children with CCHS.

The case-study design was chosen as the method of investigation because it is conducive to in-depth systematic investigation of a single individual, group, community, or some other unit (Woods & Catanzaro, 1988). The case-study design is particularly useful in investigating contemporary phenomena within their real life contexts (Woods & Catanzaro, 1988).

Setting and Sample Population

A northern California metropolitan area was the setting for this study. The sample included the families of two ventilator dependent children with CCHS.

Data Collection Instrument and Methods

The data were obtained using an open-ended interview schedule (see Appendix A) designed by the investigator. Demographic information obtained included: (a) age, (b) sex, and (c) ethnic origin of the ventilator dependent children; and (d) marital status, (e) educational background, (f) occupation, and (g) socio-economic status

of the parents. The interview schedule was designed to document each child's history and requirements for care from the parental viewpoint. The interview schedule was designed to collect data regarding: (a) the family structure, (b) the medical and developmental status of the child, (c) the type and intensity of home care arrangements, (d) the family's social adjustment, (e) the existence of support systems, (f) equipment needs, and (g) financial obligations as a result of home care of the involved ventilator dependent child.

The study data were obtained by conducting the interviews in the homes of the involved families. The interview responses were recorded per pen and paper during the course of the interview and required 1-1/2 to 2 hours.

The interview schedule was approved for use in this study by the San Jose State University Committee for the Protection of Human Subjects. Consents from all participants were obtained (see Appendix B). The families were assured that confidentiality would be maintained. The actual names are not associated with the data.

Scope and Limitations

The following limitations are acknowledged: (a) the interview relies heavily on subjective data; (b) the population is limited; and (c) the conclusions are limited.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF LITERATURE

Conceptual Framework

Orem's nursing model was selected as the conceptual framework for this study, because the major concern of the model is self care. "Self-care is the production of actions directed to self or to the environment in order to regulate one's functioning in the interest of one's life, integrated functioning, and well being" (Orem, 1985, p. 31). Self-care agency is the complex acquired ability to meet one's continuing requirements for care (Orem, 1985, p. 32). Families caring for ventilator dependent children in the home are performing complex activities that maintain life, health, and the well being of the involved ventilator dependent children.

According to Orem (1985), infants, children, adolescents, the aged, the ill, and disabled persons are dependent members within society, because they require complete care or assistance with care activities. Their well being is entrusted to responsible adults, and in so doing, these adults function in the capacity of dependent-care agency.

Self-care agency is defined by Orem as activities which meet three requisites: (a) universal self-care requisites, which include water, food, air, rest, activity, elimination,

and social interaction; (b) developmental self-care requisites, which include developmental tasks; and (c) health deviation self-care requisites, which include dealing with disabilities and/or defects. When these self-care requisites/demands are met in a sufficient manner, individuals are considered structurally and functionally whole or sound, which is congruent with a state of wellness. However, when the self-care demand exceeds the capabilities of the individual, a self-care deficit occurs. Illness, disease, or death will occur. The existence of these deficits/limitations validates nursing intervention. At this point, the individual or family should and will seek assistance from a nurse and the nurse (nurse-agency) will intervene to meet the universal and health deviation needs in a "wholly," partly or supportive/educative manner via a three-step nursing process (Orem, 1985).

Nursing is viewed as a helping service that designs, provides, and manages systems of self care and dependent care when individuals and/or families cannot (Orem, 1985). The goal of nursing is to help individuals meet their own or dependents' care demands. As previously noted, ventilator dependent children, until recently, had been restricted to hospitals. Due to technological advances, families have begun to assume greater responsibility in caring for their ventilator dependent children at home. With the advent of

specialized training, families, as opposed to or in addition to nurses, are meeting the care demands imposed by ventilator dependent children. These families are exercising their dependent-care agency.

Orem identifies the dimensions of nursing practice as social, interpersonal, and technologic. The technologic dimension encompasses the steps of the nursing process, which include: (a) diagnosis and prescription, (b) designing and planning, and (c) production and management of systems of nursing assistance. The diagnostic phase pinpoints care deficits, the design phase incorporates the identified nursing systems, and the management phase encompasses the provision of nursing care. Specific nursing actions are delineated. The management phase is most applicable to families of ventilator dependent children, who are carrying out the dependent care of these children.

In summary, Orem's model is specifically designed to meet self-care and health-deviation needs. The model is based upon a person's need and ability for care activity. Families possess a unique desire to provide dependent care for their ventilator dependent children, and due to technological advances, the capability of families to care for their ventilator dependent children at home has improved tremendously.

Literature Review

Congenital Central Hypoventilation Syndrome (CCHS) is a nonprogressive disease that primarily affects the neuromuscular control of breathing during sleep. The first case of CCHS was described in 1970 (Mellins, Balfour, & Turino, 1970; Oren, Kelly, & Shannon, 1987). Infrequent, isolated cases have been reported worldwide since the disease was initially identified. There is a lack of published information concerning the disease and its long term ramifications.

Poliomyelitis Epidemics

The experiences and health care advances from the worldwide poliomyelitis epidemic of the 1940s and 1950s serve as a model for new and evolving concepts in the management of ventilator dependent patients (Goldberg, Collen, & Monahan, 1988). Upper airway devices, artificial respiration, and the modern positive pressure ventilator were developed in response to the poliomyelitis crises. Polio survivors who were dependent upon life supportive technology, requiring part-time or full-time mechanical aids for breathing, were the first ventilator dependent children and adults (Frates, Splaingard, Smith, & Harrison, 1985).

The medical needs of the polio survivors were comprehensive and required an interdisciplinary team of physicians and allied health personnel. A regional system

of specialized health care centers evolved, the polio-respiratory centers. The birth of modern critical care and rehabilitation medicine can be traced to these centers (Frates et al., 1985). Polio survivors requiring ventilatory assistance were confined to the hospital. The collaborative efforts of physicians, allied health professionals, families, friends, and voluntary organizations helped create outreach programs from the regional polio centers which consisted of home care and other community-based living alternatives and support services.

Home Care

Modern medical technology accounts for a drastic increase in the number of ventilator dependent patients. Currently, such individuals reside for years in acute intensive care facilities, at enormous costs in human and economic terms. According to Splaingard et al. (1983), prolonged hospitalization retards children's development and may precipitate detrimental psychological effects in adults. The intensive care environment magnifies the untoward effects of prolonged hospitalization. There are rising concerns about the feasibility for safe, effective home care programs for ventilator dependent patients. Until recently, there were few viable institutionally based or

community oriented options. Home care projects are now evolving into definite programs.

Goldberg (1984) and Goldberg and Faure (1984) advocate a regional approach to home care for ventilator dependent patients. Their descriptions of the following European experiences illustrate the successful components of regional programs that implement the concept of home ventilator care.

1. The Responaut Program is a hospital based operational program which provides needed services for ventilator dependent persons in England who are either at home with family members or living in the community because of the development of other suitable alternatives. The program began in 1965 and benefits people with a highly personal home maintenance service as well as the hospital based unit.

2. The ADEP Program (Association d'Entraide des Polios et Handicapes) (Association of Mutual Help for Polio and Handicapped People) is a community based operational program in the greater Paris, France, metropolitan area. Services are provided according to a contractual arrangement with reimbursement authorities. ADEP provides equipment maintenance, quality assurance, case-monitoring, and coordination of available institutional resources. The program includes home maintenance services, independent

living centers for ventilator dependent persons, and a documentation center providing information required by disabled people to live in the community.

3. The ALLP Program (Association de la Region de Lyon Pour la Lutte Contre la Poliomyelitis) (Association of the Lyon Region for the Fight Against Polio) is a hospital based regional program which serves ventilator and oxygen dependent persons in the Lyon region of France. This program offers a computer-based coordination of hospital and home care services. The program includes an independent living center and an essential transitional care concept.

Dunkin (1983) conducted a study over a 6-year period on ventilator dependent patients with neuromuscular disorders that were managed at home by their families. Dunkin concluded that a significant benefit was the improvement in morale experienced by the patients and their relatives.

Burr, Guyer, Todres, Abrahams, and Chiodo (1983) conducted a study to document the experiences of six Massachusetts families who brought their ventilator dependent children home from intensive care units. These researchers concluded the following: (a) Without exception, parents believe that bringing their children home from the hospital has had a beneficial effect on family relations; (b) most families have reported that their children have

been either stable or medically improved since they have been home; (c) all families could identify persons whose support enabled them to cope more effectively with their situation; (d) the diversity of educational and social backgrounds among the parents indicates that these factors are less relevant to successful home care than the availability of support; and (e) despite the positive feelings of parents, they have described their loss of privacy, limited social lives, disruption of sleeping patterns, and difficult schedules as effects of home ventilation.

Splaingard, Frates, Harrison, Carter, and Jefferson (1983) conducted a retrospective study of ventilator dependent patients covering a span of 20 years. This study concluded that mortality was greater for children than for adults. For the majority of patients, the cost of management at home was significantly less than management in the hospital, depending largely on the level of nursing care required. Splaingard et al. suggest that mechanical ventilation at home may be a reasonable alternative to prolonged hospitalization for medically stable ventilator dependent children and adults.

Frates et al. (1985) concluded in a study that home mechanical ventilation with patients cared for by family and friends costs less than registered nurse or hospital care.

There was no significant difference in the number of deaths between patients cared for by registered nurses 24-hours a day and those cared for by family and friends. Frates et al. concluded that home mechanical ventilation may be a reasonably safe and cost effective alternative to prolonged hospitalization for the ventilator dependent child.

Goldberg et al. (1988) conducted a study to obtain the physician's perspective concerning the care of children at home who required prolonged life supported medical technology. Most physicians surveyed had participated in discharge planning and maintained an active role with their patients after discharge. The physicians thought that development and support of resources at the community level were essential for the success of home care.

Treatment

Oren et al. (1987) conducted a long term study of the clinical course of 6 patients with CCHS. During the neonatal period, the patients had prolonged apnea and hypoventilation, in the absence of cardiac, pulmonary, or neuromuscular disease. After an initial period of respiratory dependency, they became able to sustain normal gas exchange while awake. During sleep, profound hypoventilation developed, and tracheostomy and mechanical ventilation were required. Five of the 6 patients were maintained at home with mechanical ventilation provided

during naps and at night. None of the families required part-time or full-time nursing assistance at home.

Weesner and Boyle (1985) observed an infant in which central sleep hypoventilation was successfully managed with enterally administered doxapram. It was concluded that doxapram was useful in the short term management of the infant and that doxapram may be a useful treatment for CCHS in infancy.

Summary

In conclusion, Congenital Central Hypoventilation Syndrome (CCHS) was first described in 1970. The disease is characterized by a lack of neuromuscular control of breathing during sleep, and is treated primarily with a tracheostomy and mechanical ventilation. The medical needs of polio survivors during the 1940s and 1950s gave birth to innovative respiratory devices, which include the modern positive pressure ventilator. Collaborative outreach programs from the regional polio centers facilitated home care and other community based living alternatives and support services for ventilator dependent individuals. Home mechanical ventilation has proven to be a reasonably safe and cost effective alternative to prolonged hospitalization for the ventilator dependent child. The focus of Orem's nursing framework is self care. Families are exercising their role in dependent-care agency for their ventilator

dependent children. Families caring for ventilator dependent children in the home are performing complex activities that maintain life, health and the well being of the involved ventilator dependent children. This study assessed the needs of the family in order to explore what assistance the family needs prior to assuming the role of dependent-care agency.

Chapter 3

RESEARCH DESIGN AND METHODOLOGY

Research Design

The research was a case-study design. The case-study design was selected for this research because: (a) CCHS is a relatively new disease; (b) infrequent, isolated cases have been reported; (c) there is a lack of published information concerning the disease and its long term ramifications; and (d) the case-study design is conducive to in-depth, systematic investigations of a single individual, group, or community, and is particularly useful in investigating contemporary phenomena within its real life context (Woods & Catanzaro, 1988, p. 122).

A hypothesis was not postulated for this study. The case-study design is not conducive to the generation of valid generalizations, because there are no controls or comparisons to put the data into broader perspective (Woods & Catanzaro, 1988, p. 156). Hypothesis testing is extremely limited when the case-study design is utilized.

Instrument

The instrument used was an open-ended interview schedule, developed by the investigator (see Appendix A) based upon the literature review. Open-ended interviews are most useful when the researcher does not know all the possible alternative responses and they allow for richer and

more complex data to be collected (Lobiondo-Wood & Haber, 1990, p. 235). Data were collected from the parents of the ventilator dependent children regarding: (a) the family structure, (b) the medical and developmental status of the child, (c) the type and intensity of home care arrangements, (d) the family's social adjustment, (e) the existence of support systems, (f) equipment needs, and (g) financial responsibilities as a result of home care of the involved ventilator dependent child. Demographic information obtained included: (a) age, (b) sex, (c) ethnic origin of the ventilator dependent children; and (d) marital status, (e) educational background, (f) occupation, and (g) socio-economic status of the parents. Testing of the interview guide for content validity and clarity was performed on two parents with children with long term disabilities and intense home care needs requiring nursing assistance.

Sample

The sample for the study was convenience. Two large hospitals that possess a Class III license for treating newborn and intensive care babies were contacted. One of the hospitals granted permission (see Appendix C) to conduct the study. According to the home care department, only two families with children with CCHS were being served. The investigator contacted the two families by telephone,

explained that she was a graduate student pursuing a Master of Science Degree in which there is a thesis research component as a requirement for the degree. The objectives and procedural methods of the study were reviewed. It was explained that the families were referred by the hospital in which they receive their primary care as possible participants in the study. Both families agreed to participate in the study.

Data Collection Procedures

Permission was obtained from several sources in order to conduct the study. Clearance to initiate the study was obtained from the San Jose State University Committee for the Protection of Human Subjects (see Appendix D). Permission was granted from a large hospital in a northern California metropolitan area (see Appendix C) to contact the involved families. The participants were asked to sign a consent form (see Appendix B). The participants were assured that confidentiality would be maintained. The names are not associated with the data.

The two families were contacted by telephone to request participation in the study. The study data were obtained by conducting the interviews in the homes of the involved families. The interview responses were recorded per pen and paper during the course of the interview and required 1-1/2 to 2 hours.

Both parents in the first case were scheduled to participate in the interview session. Shortly after the arrival of the interviewer, the father had an unanticipated situation arise which required his immediate attention. Therefore, he was not available to participate in the interview. Only the mother in the second case was interviewed because she and her husband were separated and she was the primary caregiver for the children.

Analysis Procedures

The intent of this study was to gather information regarding the experiences of two families with children with CCHS, who were providing home care in lieu of hospitalization. There were no measurable variables or comparisons. Based upon the nature of the study, the data collected were summarized and analyzed in a narrative format. Statistical analysis was not indicated. The data were summarized in the following areas: (a) diagnosis, (b) hospital discharge, (c) home care and equipment, (d) psychosocial aspects, and (e) the developmental/medical status of the child.

Chapter 4

ANALYSIS OF THE DATA

This chapter describes the results of a study to identify the advantages and/or disadvantages of families providing home care to ventilator dependent children in lieu of hospitalization. A demographic description of the sample population is presented, along with data from two case interviews. Each case presentation addresses five areas: (a) diagnosis, (b) hospital discharge, (c) home care and equipment, (d) psychosocial aspects, and (e) the developmental/medical status of the child.

Demographic Description

A discussion of the demographic characteristics of the ventilator dependent children and the parents follows.

Ventilator Dependent Children

The children's ages were 4 and 5 years old. One of the case interviews involved a set of twins. All 3 children were male. One child was of Afro-American heritage and 2 of the children were caucasian.

Parents

Only the mothers of the two families were interviewed; however, demographic information was obtained about their spouses. One parent had completed 7 years of college, one parent had completed 4 years of college, one parent had completed 2 years of college, and one parent had completed

1 year of college. The mean age of the parents in the study sample was 33, with a range of 29 to 37. The ethnic origin of the parents was the same as the children. The single-parent family with only a mother was in the lower socio-economic level (<\$12,000/yr.). Prior to the recent separation of the parents, the family's socio-economic level ranged within the middle level (>\$12,000/yr.). One of the families was in the upper socio-economic level (>\$45,000/yr.).

Case Study Presentations

Case 1

Diagnosis

Case 1 is a 5 year old male. He lives with his parents and 13 year old stepsister. The mother had an uneventful pregnancy and delivery. According to the mother, the child was "born blue." As a newborn, he suffered periods of apnea during sleep for no apparent reason. The underlying etiology went undiagnosed for several months. Subsequently, the child underwent a very prolonged hospital stay. A tracheostomy was inserted when the child was 2 months old. At the age of 4 months, the child was diagnosed with CCHS. The diagnosis came about as a result of hospital-initiated consultation with community pediatric experts.

Hospital Discharge

The child was discharged home to the care of his parents at the age of 6-1/2 months. The facility in which the child was hospitalized had not previously been involved in a discharge of this nature. The family had to acquire the services of an attorney and actively pursue the hospital's support for home care in lieu of hospitalization. As far as the family was concerned, institutionalization or continued prolonged hospitalization were not viable options. The family was adamant in their pursuit for home care in lieu of hospitalization. They felt very strongly that the child would not progress as well in the hospital as he would at home in a family-oriented environment. They were very concerned that the child had only gained 3 pounds from birth to hospital discharge.

After a period of intense negotiations, the hospital/health insurer agreed to support the family in providing home care to their ventilator dependent child in lieu of hospitalization. The family was encouraged to spend as much time as possible and provide as much of the care as possible in preparation for discharge. The father's mother was also an active participant in the discharge planning and care prior to discharge home. While hospitalized, the child was maintained in an isolation room. Thus, the parents were able to spend the nights whenever possible. The parents

received instruction/training in cardio-pulmonary resuscitation (CPR) in addition to the care requirements of their child. The mother states she feels as though they were properly instructed on all phases of the care prior to discharge.

Home Care and Equipment

The hospital/health insurer agreed to provide nursing coverage to assist the family in providing care at home. The health insurer paid for in-home services, which consisted of 24-hour nursing coverage by a Registered Nurse for the first 2 weeks and 16 hours a day of nursing coverage thereafter.

The mother states it was reassuring to have the nurses on hand, but at the same time their presence was an intrusion on the family's privacy. The family initiated a weaning process to reduce the amount of nursing coverage provided in the home. The mother stated she and her husband wanted to assume as much responsibility for the care as they could and minimize the need for agency personnel in their home. The parents eliminated the weekend evening nursing coverage when the child was 2 years old. When the child was 2-1/2 years old, the parents eliminated weekend nursing coverage altogether. When the child was 4 years old, the family eliminated all nursing coverage during the day and has maintained a schedule of 8 hours of nursing service

5 nights a week (11:00 p.m. to 7:00 a.m.) since that time.

The parents increased their resource network by instructing 3 additional family members in the child's care, the maternal grandmother and 2 aunts, all of whom are able to independently provide care for the child.

The family took a 10-day vacation to Disneyland when the child was 3 years old. They managed the care without the assistance of nursing services. The mother states it was slightly taxing, but the rewards were well worth the venture. When the child was 4-1/2 years old, the family repeated the Disneyland excursion.

All of the equipment needed for home care was delivered to the home prior to discharge. The home care equipment was coordinated with equipment utilized in the hospital. At the time of interview, the child required the following equipment items: (a) portable and stationary suction machine, (b) air compressor, (c) mist, (d) ambu bag, (e) 2 small oxygen tanks for emergency, (f) portable and stationary ventilator machines, (g) generator, and (h) 24-hour battery. The California Children's Society (CCS) paid for all the equipment for the family. In addition, CCS paid the monthly maintenance insurance on the ventilators in the event of needed repairs until May 1989. CCS discontinued the payments at that time because the family's income

exceeded the eligibility requirements. The family's health insurer assumed responsibility for the monthly fee (\$254.00) since that time.

Psychosocial Aspects

The parents received counseling for 2 to 3 months prior to the child's discharge and for 2 to 3 months after the child's discharge per arrangements by the hospital. The mother states the home care aspect has been a relatively smooth adjustment for herself, her husband, and her extended family. She feels as though they quickly adjusted to having their son at home. She emphasized that it was more of an adjustment to have unfamiliar nursing personnel in the home than adjusting to the actual care for the child.

At the time of discharge, the father was attending school. He took 2 semesters off, but continued to work fulltime. The mother returned to work when the child was 1 year old. She has experienced difficulty in maintaining a job; she has worked at several different jobs since returning to work. She attributes her frequent job turnover to the increased need to take planned and unplanned time off for the care of the child, in conjunction with inflexible employers.

Initially, the child's family lived in a major urban area. When the child was 2 years old, the parents researched the various school systems and found that a

nearby community had a mainstream school program which facilitated handicapped children. As a result of this information and in preparation for the child's eventual entry into the public school system, the family sold their home and relocated.

The child has one sibling, a 13 year old sister. She is the father's daughter from a previous marriage. She has been living with the family for the past 2 years. The mother states she and her husband do not place the responsibility for caring for the child's ventilator and/or trach needs upon her. According to the mother, the sister interacts with the child "normally."

The parents have considered the option of having another child, but there was mutual agreement not to do so. The parents have received genetic counseling and have been reassured that most likely they would not have another child with CCHS. The decision not to have additional children was based upon the viewpoint that they have had to literally fight to secure the smallest of gains for their child. The child's long range course is somewhat unpredictable. The family suspects that they have yet many battles to fight.

The mother states the family's unanimous belief is that home care without a doubt is a more advantageous and humane approach to ventilator dependent children, as opposed to prolonged hospitalization or institutionalization. The

mother listed the following advantages: (a) the child's overall developmental progress has been enhanced, (b) the child is more independent, and (c) the child has been nurtured in a loving environment. The mother states the following disadvantages: (a) Additional resources are needed to care for the child at night while the family sleeps, (b) privacy in the home is forfeited when nursing personnel are present, and (c) she has not been able to work consistently on a job. She is presently working for her mother as an office receptionist. She states her mother understands her situation, therefore responds to her needs in a more flexible manner.

Development/Medical Status

The child encountered bowel problems as a result of CCHS and subsequently had a colostomy performed prior to the initial hospital discharge. He was readmitted to the hospital when he was 2 years old for an ostomy takedown procedure, which is a reversal of the process. The child has been admitted to the hospital on three other occasions with pneumonia: November 1986, January 1987, and March 1990.

The child is connected to the ventilator while napping or sleeping. The child undergoes periodic sleep studies to determine the extent of the continued need for ventilatory maintenance during sleep. The ventilator settings are adjusted according to the sleep study results. The mother

states the child responds to his "trach" as a normal body function. The child will alert his parents to the fact that he is sleepy and he needs to be "connected." The "trach" is capped throughout the day. The child requires minimal suctioning.

According to his mother, the child's developmental status is congruent with his age; however, she feels as though his speech development may be slightly slower than normal. He was toilet trained when he was 2 years old. He began speaking appropriately, utilizing full sentence structure, when he was 3 years old. The child received speech therapy once a week.

The child exhibited minimal weight gain the first 2 to 3 years. The endocrinologist attributed the child's weight problem to his bowel problems (loose stools) and placed the child on a corrective diet. The child's weight has been steadily improving according to the developmental age and weight graph.

The child began attending pre-school 3 hours a day in March 1988. He was initially accompanied by a nurse. He now attends school alone. The school and the teacher are informed of his condition. The child's parents are presently negotiating with the public school authorities. They are requesting that a trained attendant accompany the child at school at the expense of the public school system.

Case 2Diagnosis

Case 2 consists of two 4-year-old fraternal twins. The mother describes her pregnancy as a "bad pregnancy." Her pregnancy was complicated by cholelithiasis symptoms and pre-eclampsia. She gained 75 pounds and had to maintain bedrest 6 out of the 7-1/2 months she was pregnant. The twins were born prematurely at 34 weeks of gestation. The twins experienced breathing problems as a result of their prematurity, which required ventilator controlled breathing. Due to this treatment, the underlying CCHS symptoms were not readily recognized. As the twins began to grow and their lungs began to further develop, the ventilators were discontinued. It is at this time that sleep apnea problems became more apparent. Tracheostomies were inserted when the twins were 3 months old, and they were diagnosed with CCHS. The mother states the diagnosis was surprising to the physicians because the incidence of CCHS was so rare they didn't expect another occurrence that quickly, especially in the same facility.

Hospital Discharge

Prior to the birth of the twins, there had been only one other case of CCHS diagnosed at this particular hospital, which happens to be Case 1 in this study. Institutional support for home care in lieu of

hospitalization for this family was readily provided. The hospital is a constituent within a large Health Maintenance Organization (HMO). A regional program had been developed and implemented to provide the support and coordination of adults and children dependent upon ventilators to be maintained in the home setting.

The parents of Case 2 were encouraged to speak with the parents of Case 1 in an effort to gain insight into the real life issues of providing home care to a ventilator dependent child within the home. The mother states the reality of a family providing ventilator home care, and the insights provided by this family, were most valuable.

The twins were discharged home at the age of 7 months. The parents received CPR training in addition to the care requirements of their children. The mother states she and her husband were adequately prepared to care for their children at home.

Home Care and Equipment

The hospital/health insurer, as previously mentioned, had implemented a regional ventilator program. The program established eligibility criteria and provided for needed supplies and equipment and in-home nursing assistance. The program authorized 24-hour nursing coverage by a Registered Nurse for the initial period of home care. Due to a lack of in-home monitoring of services by the hospital/health

insurer, nursing coverage was provided on a 24-hour basis for a period of 1 year. The mother states she was aware of the fact that the hours were to be decreased, but because the hospital/health insurer had not initiated a weaning process, she and her husband assumed 24-hour nursing coverage was to be continued indefinitely. The mother admits that there was very little that she and her husband were responsible for as a result of the 24-hour nursing coverage.

Once the hospital realized that the family still had 24-hour nursing coverage at 1 year, they designated a case manager to monitor the continued need for in-home nursing assistance and to initiate a weaning process of nursing hours as deemed appropriate. The family was immediately cut back to 16 hours of nursing coverage per day. The family has been involved in a steady weaning process to further decrease nursing hours since that time. They were cut back to 16 hours of nursing coverage 3 days a week and 11 hours of coverage 4 days a week when the twins were 2 years old. The 11-hour days were eventually reduced to 10-hour days and the 16-hour days were reduced to one per week. The mother states it was very difficult for her and her husband to adapt to the reduction of assistance throughout the weaning process. The end goal of the weaning

process will be to reduce nursing hours to 8 per night while the family sleeps.

All of the equipment needed for home care was delivered to the home prior to discharge. The home care equipment was coordinated with equipment utilized in the hospital. Each of the twins requires the following equipment items: (a) portable and stationary suction machine, (b) air compressor, (c) mist, (d) ambu bag, (e) small oxygen tank for emergency, (f) portable and stationary ventilator machines, (g) generator, and (h) 24-hour battery. CCS purchased the ventilator machines for the family and they continue to pay the monthly maintenance fee in the event of needed repairs. The twins share a room. The equipment is accessible and placed in an organized manner.

Psychosocial Aspects

The parents began receiving counseling to assist them in coping with their children's medical problems and their changing lifestyle when the twins were 5 months old. The parents have been undergoing counseling continuously since then.

The mother states she feels isolated and alone. She relocated from another state to marry. She left behind all her friends and relatives. She states she had only been living here several months prior to getting pregnant. She immediately had to maintain bedrest due to complicating

factors as a result of the pregnancy. She was not afforded the opportunity to establish peer relationships locally. The mother worked as a Licensed Vocational Nurse prior to relocating to California. She states her nursing background has made the situation more tolerable for her.

The father is an attorney. He has not worked since the twins were born. He is on disability from a back injury. Both parents were available to care for the twins since their discharge home. The parents did not have any resources aside from the agency nursing personnel; there were no friends or family members familiar with the care and equipment required by the twins.

The parents have been separated for approximately 8 months. They see a marriage counselor once a week for possible reconciliation. The mother states the home environment is now less demanding on the twins because the household now lacks her husband's high anxiety. The mother verbalized concern regarding the possible emotional effects the twins may be experiencing as a result of the separation.

The mother attributes the twins' medical condition as a major factor in precipitating the separation. She states that she and her husband have experienced no privacy in the home since the agency personnel have been providing care for the twins. This lack of privacy has affected their sex life. She states that the responsibility for caring for the

twins just became too overwhelming for her husband. When the father moved out, he initially did not assist with the physical care of the twins. He provided for them and the mother financially. The father has now begun keeping the twins one to two times a week while the mother attends school. The mother states she realizes she needs to focus some attention on herself.

The mother states for the first year or so they were virtually captives in their own home. The husband was fearful that if the twins were exposed to "the outside" they would be susceptible to developing upper respiratory infections. Over the past few years they have been more outgoing and have allowed the twins to do the same.

The mother states there was never a question as to whether she and her husband preferred home care in lieu of continued hospitalization. She wanted to provide "as normal" a life as possible. The mother cites the following advantages of home care: (a) The parents can raise the children at home and (b) the children can lead a somewhat normal life. The mother cites the following disadvantages: (a) There is increased stress dealing with twins within itself, (b) there is lack of privacy with agency personnel in the home (no time alone for parents), (c) there is no time for oneself, (d) exhaustion from taking care of the children, and (e) irritability between the spouses.

Developmental/Medical Status

The twins' developmental progress was delayed because they were premature. According to the mother, the twins were not allowed to sit up or roll over while they were hospitalized, which in combination with their prematurity inhibited their maturational development. The mother states the twins experienced a period of rapid growth and development. She considers their maturational development normal at present. The twins appear active, alert, and well adjusted.

One of the twins was hospitalized approximately 1 month after he was discharged from the hospital due to a severe case of pneumonia. He was hospitalized for 2 to 3 weeks. The other twin was hospitalized when he was 2 years old and underwent surgery for repair of a hydrocele. The twins have not been hospitalized for any other illness or condition. They periodically spend the night in the hospital to undergo sleep studies to determine the extent of their continued need for ventilatory maintenance during sleep. The ventilator settings are adjusted according to the sleep study results.

The twins are connected to the ventilator throughout the night. They are connected to the ventilator during the day for naps only. According to the mother, the twins are beginning to try to suction themselves. They require

suctioning approximately 3 to 4 times a day. Aside from napping, the twins' "trachs" are capped during the day.

The twins received speech therapy once a week until recently. The twins initially gestured to communicate. When they began to verbalize they placed their chins over the "trach." They began speaking in full sentences when they were 3 years old. The mother considers their speech "normal."

The twins have been toilet trained since they were 2-1/2 years old. They began attending pre-school once a week around the same period. They are presently attending pre-school two mornings a week. They are not accompanied by nursing personnel during school.

Summary

In summary, Case 1 is a 5-year-old male who was diagnosed with CCHS at the age of 4 months. The family experienced resistance in their efforts to care for their ventilator dependent child at home. The family acquired the services of a lawyer and successfully pursued support for home care from the hospital/health insurer. The family views home care as a more advantageous and humane approach to care for ventilator dependent children.

Case 2 consists of a set of fraternal twins who were diagnosed with CCHS at the age of 3 months. The family experienced minimal difficulties in seeking home care in

lieu of hospitalization because the first case of CCHS diagnosed in this particular hospital had been several months prior to the birth of the twins and a regional ventilator program had been developed as a result of the initial case. The mother views home care as a more advantageous and humane approach to ventilator dependent children, but the stresses associated with home care were too overwhelming for her husband. The home care situation affected the marriage and is cited as a major contributing factor to the demise of the marriage.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to examine factors which impact families providing home care to ventilator dependent children, more specifically children with Congenital Central Hypoventilation Syndrome (CCHS). The nonrandom study sample consisted of two families providing home care in lieu of hospitalization to ventilator dependent children with CCHS. The narrative case presentations addressed five areas: (a) diagnosis, (b) hospital discharge, (c) home care and equipment, (d) psychosocial aspects, and (e) the developmental/medical status of the child. Demographic information on the ventilator dependent children and the parents was obtained.

Conclusions

The findings as a result of the data collection provided answers to the three research questions. A discussion of each question and the pertinent findings is presented.

Question 1

What are the benefits of ventilation at home? Both families cited advantages for home care in lieu of hospitalization. They both agreed that home care was a more humane approach to ventilator dependent children. The mother of Case 1 specifically states the following

advantages: (a) The child's overall developmental progress has been enhanced, (b) the child is more independent, and (c) the child has been nurtured in a loving environment. The mother of Case 2 cites the following advantages: (a) The parents can raise the children at home and (b) the children can somewhat lead normal lives. The study findings are consistent with the literature that emphasizes home care in lieu of hospitalization or institutionalization as cost effective and psychologically beneficial (Splaingard et al., 1983; Hazlett, 1989).

Question 2

What are the complications and disadvantages to home care? The following factors were cited by the two families: (a) the need for in-home nursing personnel, (b) the lack of privacy, (c) difficulty in maintaining a consistent job on the part of the mother, (d) increased stress, (e) minimal time for oneself, and (f) irritability between the spouses. The study findings are consistent with the literature which emphasizes the disadvantages of home ventilator care (Burr et al., 1983). The study findings are inconsistent with the literature that emphasizes complete family independence, i.e., no nursing assistance, in providing care to ventilator dependent children with CCHS (Oren et al., 1987).

Question 2

What is the social, emotional, and financial impact of home ventilation on the family? The parents of Case 1 pursued institutional support in their efforts to secure the right to take their ventilator dependent child home. Their persistence and endurance opened previously closed and uncontested doors within a large Health Maintenance Organization. The parents appear well adjusted to the child's medical condition and associated home care needs. The child has been assimilated into the family's pattern of living. The parents have a network of capable and reliable resources who can provide care to the child independently. The parents' marital relationship appears intact and thriving. Neither of the families were impacted financially due to the children's in-home ventilator needs. The California Children's Services and/or the hospital/health insurer provided the necessary equipment and supplies and the financing for the nursing coverage. The children appear medically stable and appear to be developing "normally." There have been few rehospitalizations, and none due to the inability of the family to cope. The study findings are consistent with the literature that emphasizes home mechanical ventilation as a reasonably safe and cost effective alternative to prolonged hospitalization for the ventilator dependent child (Frates et al., 1985).

The family of Case 2 has been disrupted as a result of the home care requirements of the children. The parents appear to have patterned their lifestyles around the children as opposed to the assimilation approach of Case 1. Both parents have not worked since the children arrived home from the hospital. Nursing coverage was provided on a 24-hour basis for the first year despite the presence of both parents in the home. The parents did not have a network of friends or relatives trained in the care of the children. The parents' social lives were limited. The literature emphasizes that successful ventilator home care is contingent upon the availability of support systems (Burr, Guyer, Todres, Abrahams, & Chiodo, 1983). The psychological benefits emphasized in the literature are inconsistent with the findings regarding the spousal relationship of Case 2 (Frates et al., 1985; Splaingard et al., 1983).

Limitations

The data collected were subjective and derived from the parental viewpoint. The case-study design is not conducive to broader generalizations of the data. The conclusions are limited to the experiences of the two families involved.

Recommendations

CCHS is a rare disease; its long term ramifications have yet to be evidenced. There needs to be continued

empirical inquiry via the case-study design in order to clarify concepts and variables for further study. The descriptive capabilities of the case-study design revealed factors which indicate that the strength of the family is: (a) contingent upon the ability of the family to assimilate the caregivers and the ventilator dependent child into the pre-existing family lifestyle, (b) the existence of a social network and/or support system, and (c) open communication between the spouses.

According to Orem (1985), families caring for ventilator dependent children in the home are performing complex activities that maintain life, health, and the well being of the ventilator dependent child; therefore, families performing activities within this context are exercising their role as dependent-care agency. The goal of nursing is to help individuals meet their own or dependents' care demands. The nurse-agency needs to intervene to assist the family members in recognizing and meeting their individual needs in order to cope more effectively with the situation.

The study yielded the following research questions for further study:

1. Which families have the ability to provide home care to ventilator dependent children with CCHS without the assistance of Registered Nurses?

2. What are the long term effects of home care of ventilator dependent children with CCHS on the children and the family? A longitudinal study could yield that information.

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APPENDIX A
Interview Schedule

INTERVIEW SCHEDULE

Demographic Information:

<u>Child</u>	<u>Parent</u>	
Age	Age	Educational background
Sex	Marital status	Socioeconomic status
Ethnic background	Occupation	Ethnic background

Psychosocial:

1. Factors influencing decision to take child home?
2. Family adjustment?
3. Who serves as the primary caretaker?
4. Have you, and do you, have extended nursing care services?
5. Do you have access to trained baby sitters?
6. Is there an extended family network available to care for the child? If so, explain.
7. Are there any additional resources in caring for the child?
8. Has the family identified a need or at some point sought family counseling? If so, explain.

Equipment Needs:

9. What supplies and/or equipment are you required to have on hand?
10. What type of instruction and/or training did you receive prior to taking the child home?

11. In the event of a power failure, do you have a plan of action? Explain.

Financial Information:

12. If you have extended nursing care services, what is the source of payment?
13. How are your equipment and supplies financed?

Child's Adjustment:

14. How long after birth was the child diagnosed?
 15. Was the child institutionalized at any given point?
 16. Ages of siblings if applicable?
 17. How does the child relate to the tracheostomy?
 18. Is the child speaking? Explain progression.
 19. How frequently, if any, has the child been hospitalized? Explain.
-

APPENDIX B
Consent Form

AGREEMENT TO PARTICIPATE IN RESEARCH
SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Davia Jackson

TITLE OF PROTOCOL: Case Study-Home Care Needs of Ventilator
Dependent Children with Congenital Central Alveolar
Hypoventilation

I have been asked to participate in a research study that is investigating the home care needs of ventilator dependent children with congenital central alveolar hypoventilation. The results of this study should further our understanding of the impact of ventilator dependent children on the family.

I understand that

- 1) I will be asked to participate in an interview about my family's experience with home ventilation which will take approximately one hour.
- 2) The possible risks of this study are the inconveniences which may occur in scheduling and conducting the interview and due to personal experiences the subject may be psychologically upsetting.
- 3) The possible benefits of this study to me are being able to share valued and rare information which will aid in the understanding of the home care needs of ventilator dependent children at home.
- 4) The results of this study may be published, but any information that can be identified with me will remain confidential, and will be disclosed only with my permission.
- 5) Any questions about my participation in this study will be answered by Davia Jackson, phone 261-9895. Complaints about the procedures may be presented to Virgil Parsons, thesis advisor, phone (408) 924-3130. For questions or complaints about research subjects' rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies & Research) at (408) 924-2480.

- 6) My consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relations with SJSU.
- 7) The refusal to participate will in no way affect my right to receive services.
- 8) I have received a copy of this consent form for my file.

I have made a decision whether or not to participate. My signature indicates that I have read the information provided above and that I have decided to participate.

Date

Subject's Signature

Investigator's Signature

APPENDIX C
Study Authorization Form

February 1990

Dear Madam:

I am a graduate student pursuing a Master of Science Degree at San Jose State University. A research component including a thesis is required for the degree.

The objective of my thesis is to gather information regarding the home care needs of ventilator dependent children with central alveolar hypoventilation syndrome. You were selected as a possible participating hospital because of the hospital's location and Class III intensive care licensure. The results of the study should increase our understanding of the home care needs of ventilator dependent children.

As per our conversation of 1/25/90, your hospital services two families with children with central alveolar hypoventilation syndrome. The names and phone numbers of the families will be given to me, but the individual families need to consent in order to participate in the study.

The data collection will consist of an in-depth interview which will take approximately one hour per family. Confidentiality will be maintained.

If you give me your permission by signing this document, I plan on obtaining consent from the two families. I plan to disclose this information to the faculty and students at San Jose State University for purposes of writing a thesis.

I have been advised that your approval is needed to conduct the research. If additional information is needed, I will be happy to supply it on your request. My phone number is 261-9895.

Thank you for your assistance.

David Jackson-Graduate Student
4539 Penniman Ave.
Oakland, California 94619

Permission granted for contacting families.

Manager, Home Care Department

Date

APPENDIX D
Study Authorization Form
San Jose State University

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

RECEIVED
MAR 29 1990

59

To: Davia Jackson, Nursing
4539 Penniman
Oakland, CA, 94619

DEPARTMENT OF NURSING
SAN JOSE STATE UNIVERSITY

From: Charles R. Bolz
Office of Graduate Studies and Research

Date: March 28, 1990

The Human Subjects Institutional Review Board has approved your request to use human subjects in the study entitled:

"Case Study: Home Care Needs of Ventilator
Dependent Children with Congenital Central
Alveolar Hypoventilation"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have any questions, please contact Dr. Stanford or me at (408) 924-2480.

✓ cc: Virgil Parsons, Ph.D.