Medically Fragile Children in Pediatric Skilled Nursing Facilities: Parents' Experience of Care

By

Sister Katherine Smith, R.N., M.S.

A Dissertation

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

December 28, 1999

APPROVED:

[redacted]

Cecelia Capuzzi, PhD, RN, Professor, Research Advisor

[redacted]

Sheila Kodadek, PhD, RN, Professor, Committee Member

[redacted]

Joyce Semradek, MSN, RN, Professor Emeritus, Committee Member

[redacted]

Beverly Hoeffer, DNSc, RN, FAAN, Associate Dean for Academic Affairs

ACKNOWLEDGMENT OF FINANCIAL SUPPORT

The National Institute for Nursing Research, NIH, Institutional National Research Service Award (T32 NR07061), Research of Families in Health, Illness, and Transition, provided partial financial support during the early years of my doctoral program. Through this fellowship award, I was able to pursue doctoral study in preparation for conducting the dissertation research. I am grateful for the support this award provided.

ACKNOWLEDGMENTS

This endeavor would not have been possible without the support, encouragement, cheers, and guidance of many people. To all of you, I am deeply indebted and everlastingly grateful.

Dissertation Committee
Cecelia Capuzzi, RN, PhD, Chair
Sheila Kodadek, RN, PhD
Joyce Semradek, RN, MSN

Readers
Sister Jeanette Heindl, RN • Roberta Sample, RN

Faculty and Students, Family Research Seminar
Oregon Health Sciences University, School of Nursing
Most especially, Kathye Grisham • Suzanne Noel

My Nurturing, Encouraging Family
Sisters of Providence • Friends • Family of Origin • Extended Family

Portland Area Pediatric Skilled Nursing Facilities
Administrators • Social Workers • Nursing Staffs

The Parent Participants
who shared their hopes, dreams, and experiences and made this study possible

A fiddler on the roof. Sounds crazy, no?
But in our little village, you might say every one of us is a fiddler on the roof,
trying to scratch out a pleasant, simple tune without breaking his neck. It isn't easy.

ABSTRACT

TITLE: Medically Fragile Children in Pediatric Skilled Nursing Facilities: Parents' Experience of Care

AUTHOR: Sister Katherine Smith

APPROVED: Cecelia Capuzzi
Cecelia Capuzzi, RN, PhD

Families whose young children are medically fragile, technology dependent, and severely neurodevelopmentally impaired face wrenching dilemmas regarding their children's post-hospital care. Increasingly, parents who deplete their own resources for providing 24-hour nursing care at home turn to pediatric skilled nursing facilities for their children's care. Yet, there was little formal knowledge about these facilities or about parents' satisfaction with care. This descriptive, exploratory study used a strategic constituent perspective of organizational effectiveness to elicit what parents described as facility strengths and weaknesses, examine factors that influence parental satisfaction with care, and survey parents' views of an ideal pediatric skilled nursing organization.

A purposively selected sample of 23 parents whose children were receiving long-term nursing care in any of three Portland, Oregon, area pediatric skilled nursing facilities participated in individual in-depth interviews lasting an average of

3½ hours. Approximately 4 months later, 18 of these same parents met for focus group interviews, which also averaged 3½ hours.

Major findings included that parents' first priority is the quality of their child's life; parents were deeply affected by who was caring for their child. Frequent staff turnover negatively influenced families' peace of mind, comfort, satisfaction, and well-being. Parents used indicators of organizational stability and family-centered, quality care to evaluate effectiveness. Parents described experiencing facilities that were effective in some areas while simultaneously not so effective in others.

Parent satisfaction was achieved through successful negotiation of decision-making partnership with staff for their child's care; establishment of supportive relationships among facility staff and other parents as well as friends and relatives; and "getting their lives back," that is, attending to other pleasures and responsibilities of life in addition to overseeing the medically fragile child's care. Pediatric skilled nursing facilities can meet parents' needs and contribute to the health of the entire family. Parents' conceptions of an ideal facility can be regarded as a resource for facilities interested in designing space and improving service.

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Families whose infants and children are medically fragile, technologically dependent, and severely neurodevelopmentally impaired face wrenching dilemmas regarding their children's post-hospital care. The survival rates of medically fragile children have improved in recent years. Children who otherwise might not have lived because of premature birth, congenital disorders, infectious diseases, or trauma are surviving the acute care phase, in part because of technological advances in medical and surgical care. In addition, the numbers of premature infants and young victims of trauma have increased (Kohrman, 1991). Many of these children endure, but with serious health and neurodevelopmental impairments, and, frequently, with continued dependence on various technologies.

Parents assume responsibility for providing complex nursing care at home as hospitals discharge children with serious health problems (Lewis, Alford-Winston, Billy-Kornas, McCaustland, & Tachman, 1992; Patterson, Jernell, Leonard, & Titus, 1994; Stevens, 1994). Care of children in their own homes is a widely-accepted ideal, yet increasingly it is recognized that this alternative is not feasible for all families. The support systems that must be in place for successful home care are extensive and are not available in all communities. Formal help from nurses, homemakers, or home health aides is often short-term and limited. If caregiving assistance of longer duration is available, it usually is provided by spouses, siblings, grandparents, and other relatives, evidence that home care of medically fragile children is often family-based rather than community-based (Brust, Leonard, & Sielaff, 1992). Not all families have the physical, psychological, emotional, social and financial resources to provide 24-hour nursing care in their homes on a long-term basis (Gale, 1989; Hazlett, 1989; Luckenbill, 1988; Sharer & Dixon, 1989).

Pediatric skilled nursing facilities are a crucial resource in the continuum of children's care options (Lewis, 1991; Malone-Rising, 1994; Millner, 1991). These facilities, a type of health care organization, are specifically designed to meet the long-term health needs of medically fragile children and their families. They provide programs of planned, individualized, comprehensive, round-the-clock nursing care to children ages 0 to 21 years. In order for children to receive this skilled level of care, a physician must certify the need for 24-hour nursing care and prescribe the admission. Whether freestanding buildings or distinct units within adult nursing homes, pediatric skilled nursing facilities are licensed by their respective states and certified for compliance with the same federal guidelines used for adult facilities accepting Medicaid patients. Unlike most adults receiving nursing home care, however, the entire population of children in pediatric skilled nursing facilities is dependent on the staff for their activities of daily living as well as for their very survival. Administrators in nearly every pediatric facility are concerned about assessing the effectiveness of their organizations and the care they provide to children and families, and appraising whether there are practices they might change (Smith, 1992).

Assessing effectiveness is complex because of the ambiguity of the concept. Several organizational theorists viewed effectiveness as the organization's ability to satisfy its constituents' judgments about its quality (Hall, 1987). One of these theorists, Seashore (1983), noted that interests and values are inherent in the term "effectiveness." He regarded "organizational effectiveness" to be a name for a class of variables defined by their use in a particular context rather than by their independent descriptive properties. Thus, "effectiveness in a particular case is whatever some constituent or some researcher making attributions to a constituency says it is" (Seashore, 1983, p. 65).

Constituents of pediatric skilled nursing facilities were considered to be the parents and the children. For this study, organizational effectiveness was defined in two ways. It was defined experientially, as parents' satisfaction with their experiences of care in the pediatric skilled nursing facilities in which their children resided. Parents are the spokespersons for their medically fragile children, expressing satisfaction or dissatisfaction on behalf of the child in care as well as of the whole family. Yet, little is known about how parents as consumers and constituents perceive effectiveness in the facilities caring for their children. There have been no formal studies gathering data on how families experience pediatric skilled nursing facilities.

Secondly, organizational effectiveness was defined theoretically, as including aspects of family-centered care, a hallmark of health care delivery embraced as a goal in many settings, and particularly in pediatric environments. The philosophy of family-centered care influences health care organizations to value (a) parent-professional collaboration, (b) flexible and responsive health care delivery systems, and (c) appropriate policies and programs that recognize and respect the needs of both the child in care and the family (Letourneau & Elliott, 1996). Yet, very little formal information exists about pediatric skilled nursing facilities and the care they provide, or about parents' perceptions of family-centered care practices in these organizations.

Whether families care for their medically fragile children at home or entrust them to the care of a health care organization, parents hold the moral authority and responsibility to safeguard their children and to administer to their needs through control over care decisions. In a health care setting, satisfactory exercise of this control may be vicarious (i.e., relinquished to trusted and competent professionals) or it may be participatory (i.e., accomplished in a partnership between parents and health care providers) (Zaner & Bliton, 1991).

As competition for health care dollars increases, the roles of consumers in many areas become more important (Schieber, Poullier, & Greenwald, 1994). At least one vision for a national long-term care program explicitly fosters consumer choice in the control of care decisions and the selection of providers (Harrington, Cassel, Estes, Woolhandler, & Himmelstein, 1994). Yet, little is known about parents' preferences and priorities in the facilities caring for their medically fragile children. Additionally, parents seldom have an opportunity to exercise consumer choice, because the overall number of pediatric skilled nursing facilities is small and the facilities usually have waiting lists.

This study is a first step toward developing a theory of organizational effectiveness that can be used to guide the operation of pediatric skilled nursing facilities. Parents are constituents of the pediatric skilled nursing organizations; the concepts of organizational effectiveness and family-centered care will be expanded by eliciting parents' perceptions. The overall purpose of this study is to develop family-based measures of organizational effectiveness that can be used to evaluate organizational performance.

In addition to expanding the concepts of organizational effectiveness and family-centered care, interviewing parents about their experiences can have a positive effect on the parents themselves. Attending to parents' perceptions elicits their value preferences (Donabedian, 1988), gives them a voice to share their vision of their child's future in order to guide and shape decision-making (Cole, 1990), and encourages them to articulate their goals, an element of satisfaction which, in turn, influences emotional well-being, health status, and therapeutic outcomes (Calnan, 1988).

Discussions of nursing home care, particularly for children, can be highly charged with both positive and negative emotions, with staunch defenders and vociferous detractors. This study will explore the experiences of those families whose children receive care in pediatric skilled nursing facilities, rather than focusing on the supportive or refutive philosophies of others who are peripheral to the families' experience. Neither will this study consider cost comparisons between pediatric skilled nursing facility care and pediatric home care. Both topics are worthy of their own studies at a future time.

CHAPTER 2

REVIEW OF THE LITERATURE

Medically fragile, severely neurodevelopmentally impaired children have a monumental impact on their families. Some families can marshal the necessary resources to provide 24-hour skilled nursing care in their homes successfully. Others attempt this intense level of care, then realize that they lack the resources to sustain it over time. Still others recognize during the child's transition from acute to extended care that they cannot provide skilled nursing care at home on a long-term basis, and must find other options for their child.

This study will address facets of families' experiences with out-of-home extended nursing care for their medically fragile, severely neurodevelopmentally impaired (MF/SNDI) children. These children, who constitute a subgroup of children with chronic illness, are identified infrequently in the literature. This chapter will review the literature describing the children and the incidence of MF/SNDI, effects on families, pediatric skilled nursing facilities, family-centered care, organizational effectiveness, and parent satisfaction or evaluation of health care.

Descriptions, Definitions, and Prevalence of Medically Fragile/Severely Neurodevelopmentally Impaired Children

As the survival rate of infants and children with complex ongoing medical problems increased in recent years, practitioners grappled with terminology with which to describe them. This section will review the major developments to describe this population of children.

Marker Diseases

In 1983, Hobbs, Perrin, and Ireys conducted a landmark study of chronically ill children in America. Known as the classic Vanderbilt Study, the project was intended to shape public policy regarding the organization, costs, and financing of services for chronically ill children and their families whose needs were believed to be little known or understood by the general public. The researchers described 11 "marker" diseases they considered as characteristic of severe chronic illnesses of childhood, and differentiated them from children's routine, acute or even fatal illnesses, stable handicapping conditions such as mental retardation, or mild chronic illnesses such as allergies or transient asthma (Hobbs et al., 1985). There were variations in the selected diseases' pathologies, trajectories, and treatments; however, they were considered characteristic of children's severe chronic illnesses because they shared the similarities of being costly to treat, requiring care over an extended time period, needing only intermittent medical care but having a daily family caregiving burden, having an unpredictable disease course, manifesting pain and discomfort, and often entailing slow deterioration and premature death (Hobbs et al., 1983). At least partly as a result of this study, the terms "chronically ill" and "children with special needs" were used to attempt to describe a specific segment of the nation's children. These terms, however, did not adequately describe a smaller but significant subgroup of chronically ill children whose complex medical problems required long-term 24-hour nursing care, nor did the diseases selected for the study capture their typical conditions.

Several other authors attempted to categorize children's conditions in an effort to define the health needs of certain segments of the childhood population (Adams & Hardy, 1989; Aday et al., 1993; Gortmaker & Sappenfield, 1984; National Health Interview Survey, 1988; Newacheck & Taylor, 1992). Variations in definitions, as well as differing data collections methods, accounted for wide ranges of estimates of the prevalence of chronic childhood illness.

Noncategorical Approach

Since the 1980s, several researchers espoused a departure from previous disease-oriented approaches to child health. They focused their discussions on describing characteristics of chronic illness as a general category, rather than on specific disease entities (Revell & Liptak, 1991; Stein & Jessop, 1982, 1989). In the ongoing effort to identify children with chronic health conditions, Stein, Bauman, Westbrook, Coupey, and Ireys (1993) proposed a noncategorical framework which specified the origin, duration, and consequences of disorders. Their framework is comprehensive and useful for describing the population of children in this study. It portrays children whose ongoing health conditions required 24-hour nursing care. Because it was comprehensive, however, it also included children whose ongoing care needs were less intense than those who required 24-hour nursing care, as well as chronically ill children who had periodic acute care episodes.

Stein and her colleagues (Perrin et al., 1993) remarked that public policy is made more difficult by a categorical approach to chronic conditions because overlaps or commonalities among conditions are not recognized. In addition, such an approach includes only those conditions which are easily able to be identified or labeled, and could exclude from policy decisions persons with multiple conditions, which occur in about 30% of affected children (p. 791).

Chronically ill children who require skilled nursing care are more similar to each other than they are to others who carry many of the diagnostic labels in the studies of Hobbs et al. (1983) and Gortmacher and Sappenfield (1984). Children with chronic illnesses with potentially serious consequences, such as asthma, cystic fibrosis, or juvenile-onset diabetes, can be expected to be ambulatory within a reasonable developmental range and to be cognitively intact, conditions rare for children needing long-term skilled nursing care.

Technology Dependent

The U.S. Congress Office of Technology Assessment (1987) identified four separate categories of children it termed "technology-dependent." Children in Group I are dependent on mechanical ventilators for at least part of each day. Group II children require extended intravenous nutrition or drug treatment. Group III children are dependent on mechanical devices for respiratory or nutritional support, such as tracheostomy tube care, suctioning, oxygen support, or tube feedings. Finally, children in Group IV have prolonged dependence on other medical devices which compensate for vital functions, such as renal dialysis, urinary catheters, or colostomy bags, and who require daily or nearly daily nursing care, including cardiorespiratory monitoring or other substantial nursing care in connection with their disabilities. These Office of Technology Assessment categories include all children requiring skilled nursing care. However, common usage of the term "technology-dependent" usually is intended to include only children in the first category, specifically those who are ventilator-dependent.

In making a case for home and community care for chronically ill children, Perrin, Shayne, and Bloom (1993) differentiated between two groups of children. One group consists of those they termed technology-dependent, who rely on mechanical devices such as ventilators, tracheostomies, IVs, or gastrostomies to compensate for the inadequate function of their own organs. The second group has medical conditions which do not necessarily require the use of medical devices but which entail a considerable burden for their caregivers. In contrast to the U.S. Office of Technology Assessment, these authors specifically excluded the latter group from those they considered technology-dependent.

Other Designations

Other practitioners coined several terms in the attempt to describe the most profoundly medically impaired group of children. These descriptors included medically-at-risk, medically complex, medically fragile, children with chronic health conditions (CCHC), children with special health care needs (CSHCN), children with complex health-care needs; children with chronic physical conditions; severely-other-health-impaired (SOHI), disabled children, and children of technology (Bleck, 1992; Cohen, 1985; Hochstadt & Yost, 1991; Richardson, Student, O'Boyle, Smyth, & Wheeler, 1992; Stein & Jessop, 1984; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993; Washington State Department of Social and Health Services, 1990; Youngblut, Brennan, & Swegart, 1994).

Researcher's Definition and Description

Throughout the course of more than three decades' experience with children throughout the United States whose medical complexities required long-term 24-hour nursing care, this researcher observed them to be both medically fragile and severely neurodevelopmentally impaired, having the following characteristics:

Medically Fragile

The origin of the children's ongoing health conditions is biologic, rather than psychologic or cognitive (Stein et al., 1993). Their conditions may be due to such causes as genetic disorders which result in severe organ system compromise, for example, Trisomy 13; to serious inborn errors of metabolism, for example, Krabbe's disease; to perinatal trauma, such as prematurity or asphyxiation; to the sequelae of infectious diseases, such as encephalitis or meningitis; or childhood trauma, such as car accidents, near-drowning accidents, shaken-baby syndrome, or intentional child battering. The children require skilled nursing care with and without medical equipment to support vital functions.

Severely Neurodevelopmentally Impaired

Children whose conditions are medically complex to the extent that they require long-term 24-hour skilled nursing care usually have experienced profound central nervous system damage due to their underlying pathologies. One major consequence of the children's central nervous system damage is respiratory impairment, including the inability to cough and control secretions, which results in frequent upper respiratory infections and which requires compensation such as ventilator support; tracheostomies and tube changes; frequent mechanical suctioning; periodic or continuous oxygen administration, chest percussion, postural drainage, and position changes; frequent administration of antibiotics for bacterial pneumonia or for complications of viral, hypostatic, or aspiration pneumonia; and, very importantly, the skilled observation, monitoring, and care planning of registered nurses.

Another major consequence of the children's central nervous system damage is severe seizure disorder, necessitating prompt intervention with medications, oxygen, and position changes and ongoing assessment of medication efficacy. This necessitates nurses' familiarity with the child's medical history and daily assessment of the fine balance between manageable sensory stimulation and the onset of seizure activity, in order to determine the amount of play, exercise, and educational intervention a child can tolerate on a given day.

The children's central nervous system damage causes inability to suck, chew, and even to swallow, resulting in the risk of aspiration pneumonia and difficulty maintaining fluid and electrolyte balance. Some children can be skillfully spoon- and cup-fed; others depend on feedings through nasogastric, jejunostomy, and gastrostomy tubes.

While the children's ongoing health conditions are not cognitive in origin, cognitive impairment often results. Many children are sensory-impaired, with cortical blindness and deafness. Their levels of awareness are limited. Their developmental ages can be scattered; overall, however, almost all the children's developmental levels score at less than 12 months and most at less than 3 months. Few of the children requiring 24-hour nursing care are ambulatory; those who walk usually need personal assistance and assistive devices to do so. Many lack the developmental achievements of head or trunk control, sitting balance, or the ability to roll over. Few can crawl or pull themselves to a standing position. Many lack the fine motor coordination required for reaching purposefully, grasping, or transferring an object from hand to hand. They rely on others to position them in proper body alignment, utilizing foam wedges and pillows when the children are lying down, and various head, trunk, and extremity supports when they are in their wheelchairs.

Medically fragile, severely neurodevelopmentally impaired children (MF/SNDI) meet the definition in one or more categories of dependence on technology as used by the U.S. Office of Technology Assessment (1987). While a percentage of the children depend on ventilator assistance (Group I), most fall into Groups II-IV, and in general use of the term, would not be considered "technology-dependent."

Prevalence

Because of the many definitions used to identify medically fragile children, estimates of their numbers also vary widely. Estimates of children with disabilities include the numbers of those who are chronically ill, as well as those whose disabling conditions have fewer chronic health implications, such as hearing and vision impairments, developmental disabilities, and learning disabilities. Estimates of childhood chronic illness include the numbers of children who are technology-dependent, as well as those whose health conditions, such as asthma, leukemia, diabetes, and cardiac disease, are less likely to be reliant continuously on technological devices. In turn, estimates of the numbers of children who are technology-dependent include those who are medically fragile and severely neurodevelopmentally impaired, as well as children who are ventilator-dependent but neurologically and cognitively intact.

The Vanderbilt Study of 1983 (Hobbs et al., 1985), the cornerstone for many researchers' estimates of the number of chronically ill children in the United States, and other studies attempted to estimate the prevalence of medically fragile children. Their estimates varied with the definitions used and the conditions included (Adams & Hardy, 1989; Aday et al., 1993; Center for Disease Control, 1995; Hobbs et al., 1985; Newacheck & Taylor, 1992; Perrin, Shayne, & Bloom, 1993). None of these estimates adequately addressed medically fragile/severely neurodevelopmentally impaired children exclusively.

The estimate of prevalence most relevant to the population of children in this study was based on an unduplicated count of children in Massachusetts aged 3 months to 18 years who required at least one form of technological health support (Palfrey et al., 1994). Based on the 1990 U.S. census figures, the results of their analysis estimated that 0.16% (2,237) of Massachusetts children ages 0 to 17 years were assisted by medical technology, as were 101,800 children nationwide. Data in this study were collected about many children who would be considered medically fragile/severely neurodevelopmentally impaired, although other children in the count were no doubt more medically stable.

In summary, defining and estimating the numbers of children who require 24-hour nursing care outside their family homes is complicated by the need to consider both medical condition and care requirements. Some researchers categorized children's conditions according to diagnoses; others argued that the specific diagnostic label was not descriptive of the impact on children's lives and those of their families and that it was more useful to consider the physical, social, intellectual, and psychological consequences of children's chronic conditions.

The most relevant prevalence rate for this group estimates that 0.16% of children 0 to 17 years nationally require technology assistance (Palfrey et al., 1994). Medically fragile, severely neurodevelopmentally impaired children are a subcategory of technology-assisted children and, therefore, their prevalence rate would be smaller.

Organizational Effectiveness

Organizations are complex systems with multiple functions and programs, multiple goals that may be conflicting, and multiple constituents that may have differing expectations. For over 60 years, researchers have studied organizations in attempts to define them and to understand what made them more or less effective. While conceptualizing organizations, researchers focused on different facets, such as the resources an organization requires, its internal processes, or accomplishment of its goals. Differences in analysts' perceptions were due at least in part to their individual values and preferences. Organizational analysts examined effectiveness from a variety of perspectives. Whether viewing an organization from within or outside and from diverse vantage points, people's positions relative to an organization and their disciplinary frameworks influence their perspectives of it. For example, consumers, employees, regulators, sponsors, economists, and social scientists can be expected to have various perspectives of a health care organization.

Differences in analysts' viewpoints and emphases lead to variations in definitions of organizations as well as of organizational effectiveness and the indicators considered important in its evaluation.

Definitions and Models of Organizations and Effectiveness

Organizational analysts focused on various elements of organizations, including efficiency (Weber, 1947); efficiency and effectiveness (Evan, 1976); goal achievement (Connor, 1980; Etzioni, 1964; Price, 1972); system resources (Seashore, 1983); constituent satisfaction (Cummings, 1983; Seashore, 1983); participant opportunities (Cummings, 1983); systems theory (Evan, 1976); political-economic perspectives (Nord, 1983); and adaptability (Bennis, 1966; Kotter, 1978; Schein, 1970). Different ways of conceptualizing organizations result in different definitions of organizational effectiveness.

Models differ in complexity as well. In the simplest models, which focus on a single dimension, organizations are considered effective to the extent that they achieve their goals (Etzioni, 1964; Price, 1972); acquire scarce and valued resources (Hall, 1987); perform well on carefully analyzed major tasks (Georgopoulos, 1986); adapt, change, and continue to be viable (Schneider, 1983); or have a high level of healthy and efficient internal processes (Daft, 1989).

Other models integrate multiple dimensions of organizational effectiveness, and are based on the assumption that organizations are more complex than a single dimension reflects. In these models, organizations are viewed as articulating diverse goals, acquiring an array of resources, performing a host of tasks, producing multiple results on a variety of time frames, having a number of constituents, and thus having the capacity to be simultaneously effective in some areas and less so in others (Hall, 1987).

All models emphasize important elements of organizations; however, no satisfactory model was found that encompassed all major aspects of organizations or organizational effectiveness. Cameron and Whetten (1983) concluded that there cannot be one universal model of organizational effectiveness because of variations in the term's meaning and use. Seashore (1983) held that any given set of indicators of organizational effectiveness should be regarded as only a partial representation, and that researchers should make explicit choices about which organizational features were to be evaluated.

Two models reflecting multiple dimensions of organizations and their effectiveness, the systems model and the strategic constituencies model, were used in this study because they most approximated this researcher's conception of pediatric skilled nursing facilities and parents' relationships to them. The systems model regards organizations as complex social systems which incorporate many individuals and groups and engage in multiple functions. As social systems, organizations construct identifiable yet permeable boundaries determining which elements are inside or outside the entity. They establish purposive goals and structure their members' activities toward achieving them, pursuing multiple objectives simultaneously with a variety of timelines. Organizations are open systems, continuously interacting with and creatively adapting to their environments in order to survive. They acquire input elements from their environments, transform them through specific processes, return outputs to their environments in a mutually beneficial relationship, and provide evaluative information regarding their processes. An organization's qualities arise from the relationships among its parts and its environment (Bennis,1966; Bolman & Deal, 1991; Cotton & Oransky, 1980; Daft, 1989; Evan, 1976).

Researchers using a systems model select any combination of indicators of inputs, transformations, outputs, feedback effects, and the environment that assess the areas of interest. The type of organization studied influences the specific indicators of effectiveness that researchers select to evaluate. For example, a manufacturing organization requires raw materials as part of its inputs, while a service organization such as a health care facility requires patients. Factors assessing inputs may also include indicators such as the organization's bargaining position, its ability to recruit and retain employees, its environmental scanning, and its responses to environmental change. A researcher studying pediatric skilled nursing facilities might explore the organization's ability to obtain necessary resources, such as staff, equipment, supplies, and funding and how it responds to responds to regulatory requirements. Transformation indicators of organizational effectiveness include measures of internal health and efficiency, and researchers may evaluate factors such as team spirit, interpersonal communications, rewards and sanctions, and decision-making. In a pediatric skilled nursing facility, researchers might explore such indicators as how decisions are made regarding the child's care, what kinds of support parents experience, and whether the facility adapts readily to families' needs. Indicators assessing an organization's outputs may include factors such as growth, market share, efficiency, profitability, and employee satisfaction (Campbell, 1976). Output indicators in a pediatric skilled nursing facility might include the facility's sense of its own mission, consonance between the family's and the facility's goals for the child, and parental satisfaction with care.

The strategic constituencies model, also called participant satisfaction, is based on the perspective that organizations have multiple constituencies, that is, individuals and groups whose lives are significantly affected by the organization and thus have some stake in the entity's performance. This model includes organizational goals, inputs, processes, and outcomes, but focuses on satisfaction of the constituents, as well as recognizing social responsibility to the community as part of the external environment (Cameron, 1981). Because of the diversity of their perspectives and interests, different constituencies can have various criteria for evaluating the organization's effectiveness. The strategic constituencies approach leads to a variety of indicators valued differently by various stakeholders, such as clients' interest in quality services or products, owners' interest in financial return, employees' concern with pay and work satisfaction, and the community's concern with societal effects (Campbell, 1976). This study viewed parents as key constituents of their children's pediatric skilled nursing facilities and focused on factors that influenced their satisfaction with care.

Effectiveness in organizations is related to every aspect of organizational life: its structure, its goals, its culture, its behavior, its decision-making processes, and its relationships with internal and external environments, including its constituents. This study was limited to the effectiveness of pediatric skilled nursing organizations from the perspective of parents' descriptions of their experiences with the facilities.

Organizational Culture

Organizations have their origins in the culture of their time; the broad societal culture of their founders influenced the original organization, and current societal culture influences current organizational members. The nature of an organization's business and its business environment also contribute to the development of its culture. Some analysts describe organizational culture as beliefs, values, norms, rituals, and stories which people create as a way of constructing meaning out of events they experience as illogical and confusing (Beckhard & Harris, 1987; Bolman & Deal, 1991). Others look beneath the symbols to determine why the contradictions existed. Their perspective is that groups which work together for a period of time, successfully surviving according to certain practices of adaptation to internal and external influences, gradually accept the values underlying the survival solutions and develop shared, unconscious assumptions of reality, which become visible in values, philosophies, artifacts, and the created environment (Ott, 1989; Schein, 1985).

Perceptions and beliefs about the structures and functions of organizations influence organizational culture. Members of the organization perform according to their perceptions of reality. An organization which views its primary purpose as goal attainment and rewards its members only for achievement of established goals is likely to promote a culture that gives little emphasis to other aspects of the organization, such as the quality of work life. An organization which recognizes various categories of persons who are significantly affected by the entity's performance is likely to encourage a culture which welcomes feedback. A pediatric skilled nursing facility which values families, their needs, and a collaborative approach incorporates family-centered care practices into its culture.

Organizational leaders powerfully influence the formation of the organization's culture. They embed and transmit organizational culture by what they believe to be important, what they reward and promote, how they react to critical incidents and crises, and the criteria they use for recruitment, selection, and termination of staff. They pursue and incorporate other members who share their values, assumptions, and theories for success; these new members move into management and executive positions and recruit additional members with similar views. However, individuals bring different needs, personalities, experiences, and emotional and cognitive coping styles to the group. The combination of individual and group strengths and interactions also contribute to the unique characteristics of the culture each organization develops (Ott, 1989; Schein, 1985). Key people leading change efforts from critical posts is an important element to organizational change in response to constituent satisfaction issues (Pettigrew, Ferlie, & McKee, 1992).

Family-Centered Care

A philosophy of family-centered care has been an integral part of nursing at least since the time of Florence Nightingale (Ham & Chamings, 1983; Kodadek, 1979). Family-centered care is often described in current literature as receiving emphasis in 1987, with a report by then Surgeon General, Dr. C. Everett Koop, calling for a national campaign to address the needs of children with special health care problems and enumerating elements of a family-centered approach to health care services (Department of Health and Human Services, 1987). That same year, the Association for the Care of Children's Health published a detailed list of family-centered care elements (Shelton, Jeppson, & Johnson, 1987). That list has been refined and restated by various authors, but most agree on the following key elements: the family as the constant in the child's life; family/professional collaboration; exchange of complete, unbiased information; implementation of emotionally and financially supportive policies and programs; respect for the diversity of families; respect for diverse coping methods; encouragement of peer networking and support; incorporation of children and family developmental needs;

coordination of services and support; and appreciation of families as families (Ahmann, 1994; Brown, Pearl, & Carrasco, 1991; Shelton, Jeppson, & Johnson, 1992; Shelton & Stepanek, 1995).

A family-centered care philosophy has been advocated for care in multiple settings including: maternity units; neonatal care units; pediatric intensive care units; neurotrauma units; general hospital units; community-based care systems; home, with technological support; pediatric medicine; and by pediatric nurse practitioners caring for chronically ill children (Bond, Phillips, & Rollins, 1994; Cohen, 1995; Diamond, 1994; Haas, 1992; Lumley & Davey, 1987; Pierce & Frank, 1992; Richmond & Craig, 1986; Rushton, 1990; Stolte & Myers, 1987). Family-centered care was provided to the residents of an adult nursing facility (Hargis & Quigley, 1984). After an extensive literature search, however, no articles were found related to family-centered care in pediatric long-term care facilities.

Partnerships between parents and health care professionals are highly valued by families (Blaine, Rosenbaum, & King, 1995). Many authors use the terms "collaboration" and "partnership" interchangeably; although collaboration can be considered an element of partnership, both terms imply mutual respect and understanding of parents' and health care professionals' roles and the interdependency between them (Council of Scientific Affairs, American Medical Association, 1993; Haas, Gray, & McConnell, 1992; Simeonsson, Edmondson, Smith, Carnahan, & Bucy, 1995). DeChillo, Koren, and Schultze (1994) found a very strong relationship between collaboration and parent satisfaction.

Parent/professional partnerships described in the literature range from sharing the hospitalized child's nursing care to parents' full participation in policy development, program implementation and evaluation, and coordination of family services. Partnership between parents and health care professionals incorporates several dimensions, including characteristics of families, professionals, and the service delivery process; education and support of both parents and staff; competence; establishment of trust; autonomy; fulfillment of expectations; communication and information-sharing; negotiation; balance of power; decision-making agency; and evolution over time (Calnan, 1988; Casey, 1995; Coyne, 1996; DeChillo et al., 1994; Dunst & Trivette, 1996; Foley, 1993; Haas et al., 1992; Kirschbaum & Knafl, 1996; Odle, 1988; Stepanek & Ahmann, 1995; Thorne & Robinson, 1988). In their research with frail older people, Harvath et al. (1994) borrowed terms from anthropology for the valuable cosmopolitan, or universal, knowledge nurses have and the local, or family, knowledge caregivers have. They promoted nurse/caregiver partnerships, based on the mutual benefit of blending both realms of knowledge.

Most parents want to participate in making decisions for their children in hospitals, clinics, and other health care settings. DeChillo et al. (1994) found that, for families, the overarching characteristic of a collaborative relationship is the sharing of responsibility and power by parents and professionals. In research with chronically ill children and their families, a common finding was parents' need to have some degree of control regarding decision-making (Kirschbaum & Knafl, 1996). Kirschbaum (1996) observed that in the process of participating in treatment decisions, parents defined and redefined who they were in relationship with their child. Ethically and legally, parents are regarded as rightful decision-makers for their children (Blustein, 1993). Some parents, however, feel inadequate and uncomfortable being asked to take responsibility for certain medical decisions and abdicate their roles with relief (Kirschbaum & Knafl, 1996). Other parents may have been thwarted in their decision-making efforts by health care providers' control over interactions, such as deciding the time and place for them, controlling the flow of information, using technical language or jargon, doing most of the questioning and interrupting, maintaining formal titles while addressing parents informally, precluding comprehensive parental understanding by withholding crucial decision-making criteria, or censuring parents when they disagreed with the professionals' opinions (Anderson & Hall, 1995; Schlomann & Fister, 1995). Family-centered care, which recognizes family strengths and individuality and respects different methods of coping, promotes parent/professional collaboration for families who desire dependent as well as interdependent decision-making.

This study is concerned with pediatric skilled nursing facilities, organizations in which medically fragile/severely neurodevelopmentally impaired children and their families receive long-term care. Parents comprise a strategic constituency of their child's facility. It is vital to consider parents' perspectives of organizations and their perceptions of organizational effectiveness, to which family-centered care contributes.

In summary, efforts to define organizations and to develop comprehensive models and measures of organizational effectiveness have been impeded by the complexity of these concepts. The more useful organizational models are those which are more inclusive. Researchers must analyze which elements of organizational effectiveness are relevant to their particular areas of study, and develop a set of measures that are meaningful to the organization's internal and external constituents. This study will begin such a process for pediatric skilled nursing facilities by eliciting elements of organizational effectiveness meaningful to parents, a strategic constituency of these facilities. Family-based measures can then be developed to be used for evaluating organizational performance.

Organizational culture manifests the beliefs, values, and norms that become unconscious assumptions within the organization. These beliefs and values are reflected in rituals and practices. Organizational leaders play strong roles in forming or changing the culture.

Family-centered care contributes to organizational effectiveness. When it is an integral component of the culture, organizations promote, among other family advantages, parent/professional partnerships, including parental participation in decision-making.

Parent Satisfaction

Satisfaction, the fulfillment of a need or want, is shaped by the difference between what people expect and what they experience. Satisfaction is driven by quality; in a health care organization, the quality of care provided is a dimension of effectiveness. In a Gallup Organization survey of customer satisfaction (American Health Care Association, 1996), quality was depicted as a pyramid. The first two levels, basic and expected quality features, were often taken for granted, resulted in neutral feelings when provided, but had to be provided consistently to meet the fundamental expectations of the consumer and to avoid anger and dissatisfaction. The higher levels, desired quality and unanticipated quality, were value-added features above those of basic and expected quality, and resulted in customer satisfaction and loyalty (p. 2).

Assessing parents' satisfaction is critical because their views can be used to make constituent-relevant changes for appropriate organization and delivery of care, particularly when funding is finite (Calnan, 1988; Kirschbaum, 1996). Families benefit from honest communication of their perceptions of organizational performance through recognizing their own strengths, fortifying their parental role of responsibility for their children's care, and sharing relevant knowledge, which is power. Organizations benefit from families' perceptions which can provide a basis for organizational focus, priorities, and internal warning of problem patterns (Shaw & Whelan, 1989).

Lay evaluation of health care can be influenced by a variety of factors, including the evaluator's images of health care in general, value preferences, the evaluator's perception of individual responsibility, the evaluator's view of sources of problems, the evaluator's level of experience with health care, the specific goals and expectations for persons receiving care, and the social-political values of the health care system (Donabedian, 1988). Researchers have raised doubts about the reliability of patient/parent satisfaction assessments due to: providers imposing their own values in the way questions were asked; practitioners' bias in favor of either technical care or managerial interests; superficiality of the assessment areas; respondents' conflicts with staff over caregiver roles or degrees of control; respondents' disinclination to answer freely when they or their family members are dependent on the provider; and perceptions that tend to change over time (Calnan, 1988; Donabedian, 1988; Kirschbaum, 1996; Maas, Buckwalter, Kelley, & Stolley, 1991; Pearson, Hocking, Mott, & Riggs, 1993; Vuori, 1994). Yet, without eliciting accurate information, little can be known about the comparison of parents' perceptions of organizational performance with those of the provider.

Several researchers studied aspects of families' perceptions of needs and organizational performance, using a variety of methodologies: survey questionnaires (American Health Care Association, 1996; Baine, Rosenbaum, & King, 1995;

Budreau & Chase, 1994; Furse, 1983; Maas, Buckwalter, Kelley, & Stolley, 1991; Rawlins, Rawlins, & Horner, 1990; Rosenbaum, 1996; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989); a combination of survey questionnaires and informed observers (Pearson, Hocking, Mott, & Riggs, 1993); qualitative interviews (Grant & Hrycak, 1987; Kirschbaum, 1996); and multiple case study (Johnson, Morton, & Knox, 1992). Of these 12 studies, 6 dealt with families with members in long-term care facilities. There was no mention in the literature, however, regarding children in long-term care facilities or parental satisfaction with the performance of such organizations.

Parents comprise an important constituency of the pediatric skilled nursing facilities caring for their children. Although there can be barriers to obtaining parents' authentic assessment of care, both families and organizations benefit from the exchange. Despite an extensive search of the literature, no studies related to parent satisfaction with their children's long-term care facilities were found.

In summary, the review of the literature revealed a paucity of information related to the population of children on which this study focuses: medically fragile children who, because of medical complexities and neurodevelopmental impairments, require 24-hour skilled nursing home care. Current literature does not adequately describe them; they are folded into general descriptions of children with special health care needs or technology-dependent children. Similarly, there are no satisfactory estimates of the numbers of these children nationally; they are included in broader definitions and calculations of incidence. No studies were found of children requiring care in pediatric skilled nursing facilities, the facilities themselves, their effectiveness, their culture including family-centered care, the families' experience, or parents' assessment of their care.

There was abundant literature regarding diverse theories of organizations and organizational effectiveness. Some organizational theorists advised researchers to recognize the complexity of definitions and models, to acknowledge that any set of organizational effectiveness indicators can be only a partial representation of the entire organization, and to make explicit choices about which organizational feature would be evaluated.

Among other models, organizations were described as open systems interacting with their environments, with multiple internal and external constituencies. To this researcher, the open systems model provides the most comprehensive perspective of an organization's major functions. This study used the elements of open systems as a framework for organizing the content of parent interviews. Many categories of internal constituents can be identified, such as patients, families, employees, and volunteers; external constituents might include groups such as regulators, legislators, and the public itself. The strategic constituencies perspective was included in this study because it is consistent with the researcher's experience and because parents were shown to possess valuable experiences with the facility which can benefit the organization as well as themselves in their sharing.

Organizational culture refers to the organization's daily way of life that reflects its beliefs and values. This study explored parents' descriptions of their experiences as constituents and how they experienced family-centered care. The study also explored factors that influence parents' satisfaction with their children's care.

CHAPTER 3

DESIGN AND METHODS

Design

This descriptive, exploratory study of parents' perceptions of the organizational effectiveness of the pediatric skilled nursing facilities caring for their medically fragile, severely neurodevelopmentally impaired (MF/SNDI) children was designed to answer the following questions:

1. How do parents describe their experiences with the pediatric skilled nursing facilities caring for their children?

2. How do parents experience organizational effectiveness or ineffectiveness? More specifically, how do parents describe the family-centered care elements they experience in pediatric skilled nursing facilities? What do parents identify as the strengths and weaknesses of the facilities caring for their children?

3. What factors affect parents' satisfaction with their experiences with pediatric skilled nursing facilities?

4. What features do parents include in an ideal pediatric skilled nursing organization?

Parents whose children were in pediatric skilled nursing facilities in a metropolitan area of Portland, Oregon, participated in individual in-depth interviews developed and conducted by the researcher. Most of these same parents participated in focus group interviews developed and conducted by the researcher approximately 4 months after their individual interviews.

Setting

At the time of the study, six facilities provided skilled nursing services to medically fragile, severely neurodevelopmentally impaired children in Oregon. Three facilities in the greater Portland metropolitan area were selected as sampling units for this study because their patient populations were similar to the types of children cared for in pediatric skilled nursing facilities nationwide and had sufficient numbers of children whose families met the criteria for inclusion in this study. In addition, they were geographically accessible for both the individual family interviews and the focus groups and the researcher had professional contacts with the facilities, which facilitated access to the families. One facility in a smaller urban area of the state was invited to participate but did not respond to the invitation. The two remaining Oregon facilities were in remote areas and were not selected for this study because of difficulties in geographic accessibility. (See Appendix A for a sample of the letters of support and access received from the three facilities selected for the setting.)

The three facilities included in the study ranged in capacity from 12 to 56 pediatric patients, and from 56 to 175 total patients. The facilities were designated by the sizes of their pediatric patient populations. Facility A-12, located within the city limits, was a proprietary organization with a 12-bed pediatric unit within its total of 175 patients. Facility B-19, located in a suburban area, was a proprietary organization with 19 pediatric patients among its total of 128 patients. Facility C-56, located within the city, was a nonprofit organization and was the state's only freestanding pediatric long-term care entity. Facility C-56 accepted children who were residents of Washington State as well as of Oregon; the other two facilities did not have a practice of admitting out-of-state residents. The data from parents of children residing in Facility C-56 provided perspectives from residents of two states. These data allowed an exploration of families' experiences when they crossed state boundaries to access health care for their children.

Sample

Sample Criteria

This study used a purposively selected sample of families whose children received care in any of the three identified pediatric skilled nursing facilities. For the purposes of this study, "family" was defined in accordance with the 1985 Department of Family Nursing, Oregon Health Sciences University School of Nursing definition: "a social system composed of two or more persons who coexist within the context of some expectations of reciprocal affection, mutual responsibility, and temporal duration. The family is characterized by commitment, mutual decision making, and shared goals" (Hanson & Boyd, 1996, p. 6). For this study, parents were the family spokespersons. "Parent" meant birth mother and/or father; mother with step-father; or father with step-mother. Surrogate parents, for example, custodial grandparents, foster parents, aunts, or uncles were not included in the sample. Their histories with the children were expected to be different from those of biological parents and birth parents with step-parents; for example, surrogate parents do not ordinarily experience comparable degrees of grief and guilt regarding the child's condition (Hobbs, Perrin, & Ireys, 1985). Sample criteria also included ongoing legal or moral decision-making responsibility for the child and repeated contact with the facility while the child was in care.

Parents selected for the sample in this study were fluent in speaking and understanding the English language. Interviews are speech events, and the researcher was fluent only in English. Sample selection targeted parents whose children were admitted for care less than 2 years prior to the individual interview, as well as those whose children had been in facilities for longer periods, in order to discover whether parents described similar experiences relative to the lengths of time their children received care and in order to compare these findings with what was reported in the literature.

In summary, the criteria for inclusion in the sample of this study were as follows. Participants were:

1. Biological or step-parents of a medically fragile, severely neurodevelopmentally impaired individual 0 to 21 years of age receiving long term care in a pediatric skilled nursing facility in the Portland, Oregon, metropolitan area;

2. Legally or morally responsible for the child and having repeated contact with the facility while the child was in care;

3. Fluent in speaking and understanding the English language; and

4. Willing to participate in the study.

The child's diagnosis was not considered as a criterion for inclusion in the study; the consequences of the child's condition, not the diagnostic labels, were considered relevant (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). Children who require 24-hour skilled nursing care have many nursing needs in common, regardless of their ages or diagnoses. For example, many children with various diagnoses require oxygen, mechanical suctioning, electronic and visual monitoring, and mechanical equipment to maintain their respirations; skilled feeding techniques or electronic feeding pumps to maintain their nutrition and hydration; and careful administration and monitoring of medications to control seizure activity.

Sampling Procedure

The researcher provided the facilities' social workers with the criteria for inclusion in the study sample, and asked them to invite parents who met the criteria to participate in the interviews. Pediatric skilled nursing facility social workers worked closely with families; they were knowledgeable and qualified to determine which parents met the study criteria. The social workers requested parents' permission for the researcher to contact them by telephone. Each facility's social worker provided the researcher with a list of parents willing to be contacted.

There was a potential that social workers might select families for whom they felt an affinity and who they believed would provide positive responses about the facility. To forestall this possibility, the researcher met with the social workers to provide a thorough explanation of the purposes of the study. The researcher explained to the social workers and, subsequently, to the parents that the study's primary purpose was an exploration of parents' experience, rather than an assessment of individual facilities.

Following this initial contact, the researcher telephoned parents to review the purpose of the study and to invite them to participate in an initial interview which was estimated to take 2 to 3 hours, and a subsequent group interview which also was estimated to take 2 to 3 hours. All invited parents agreed to participate in the study.

Sample Size

Because this study was exploratory, the number of parents in the sample was determined by the data, with sampling continuing until no new information emerged. The parents of 16 children were included in the study.

The children's length of stay in pediatric skilled nursing facilities at the time of the initial individual interview for this study ranged from 7 months to 15 years, 8 months ($M = 5.52$ years; $SD = 4.83$). Parents in this study were sorted into their children's long-term length-of-stay categories and purposively selected for participation. The categories were: (a) stays of less than 2 years; (b) stays of 2 to 4 years; and (c) stays of more than 4 years.

The sample was intended to include the maximum range of experience. The sample included the parents of five children admitted for less than 2 years; the parents of four children who had been in care for 2 to 4 years; and the parents of seven children who had been in care for more than 4 years. The numbers of parents interviewed in the first two length-of-stay categories were expanded during the study because these shorter-term parents seemed to relate events with more specificity. The numbers also were expanded to assure inclusion of the maximum numbers of available parents from Washington State and those whose children were receiving care in the smaller pediatric units. In the first two categories, all parents who volunteered were included. In the last category, 13 families volunteered to participate; 7 families were selected based on their accessibility.

The sample families' configurations resulted in a maximum of two persons from each child's family being included in the initial interview. Nine mothers were interviewed singly and seven couples were interviewed together, totaling 23 participants: 16 mothers, 6 fathers, and 1 step-father. Eighteen of these parents participated in one of the three scheduled focus group interviews.

Sample Characteristics of Children

The 16 children represented by the parents participating in this study ranged in age from 3 years, 9 months, to 19 years, 5 months (*M* = 13 years, 4 months; *SD* = 4.35). Eleven were boys; five were girls. Table 1 provides the data about the ages at which the children experienced the onset of symptoms of their medically fragile conditions, and the ages at which they were diagnosed. The time lag between symptom onset and diagnosis for half of the children was described by some parents as stressful and frustrating.

Table 1

Age of Children at Onset of Symptoms and Diagnosis

Age	Onset of Symptoms		Diagnosis	
	n	*P*	*n*	*P*
Birth	10	62.50	6	37.50
< 1 week	2	12.50	2	12.50
1 week to 3 months	3	18.75	0	0.00
>3 months	0	0.00	2	12.50
> 6 months	0	0.00	3	18.75
> 12 months	1	6.25	3	18.75

The types of conditions which were primary diagnoses are typical of children whose medical conditions are complex and who require extensive nursing care. Nine children had congenital malformations of the nervous system; two had chromosomal abnormalities; one had neonatal metabolic encephalopathy; two suffered prenatal or neonatal infections of the nervous system; and two experienced traumatic anoxic encephalopathy.

The children had numerous secondary conditions and surgical procedures as consequences of their primary medical problems. All of the children in this study were non-ambulatory; all had severe seizure disorders; all were developmentally delayed; none could feed him/herself or independently attend to other activities of daily living. Other frequent conditions included: respiratory impairment; tracheostomy; cerebral palsy; feeding problems requiring procedures such as fundoplication and placement of a nasogastric or gastrostomy feeding tube; orthopedic problems requiring surgery, frequent positioning, and regular physical therapy for such needs as range of motion and weight bearing; cardiovascular problems; immunosuppression; cortical blindness and cortical deafness.

Children received care at home for lengths of time ranging from 3 weeks to 13½ years (*M* = 6.22 years; *SD* = 3.95). While receiving care at home, many of the children required numerous hospitalizations (see Table 2). Parents typically described these episodes as times of stress, with anxiety about the medically fragile child in the hospital, children left at home, transportation to see the child, and medical expenses. The hospitalizations in Table 2 did not include countless urgent trips to the emergency room and routine or urgent trips to doctors' offices.

The children's ages at admission to the pediatric skilled nursing facility ranged from 9 months to 13½ years (*M* = 6 years, 10 months; *SD* = 3.95). One child was cared for at home for 3 weeks, then received medical foster care until admission to the facility at age nine months.

Table 2

Number of Inpatient Admissions Experienced Prior to Long Term Care Admission

Number of Inpatient Admissions	*n*	*P*
1	5	31.25
2 to 5	4	25.00
6 to 10	2	12.50
11 to 15	1	6.25
"Too many admissions to count"	4	25.00

Parents described seeking and utilizing various combinations of resources to obtain the care their children needed. Eight children were admitted to their nursing facilities directly from home. Three were admitted to the nursing facility under a plan of short term care (up to 90 days) but remained in the facility for long term care. Three children were cared for at home, had respite (short term) care in the facility, returned home for several months or even years, and were eventually admitted for long term care. Four families utilized multiple skilled nursing facilities, with children moving because of age and size, location of the family's residence, or parental choice. Three families utilized medical foster care for their children prior to admission for long term pediatric skilled nursing care; two families utilized multiple medical foster care homes. One family utilized multiple resources, including medical foster care, in-home nursing, and respite care before their child's admission for long term care. The numbers in the resource categories overlap according to variations in use; they therefore exceed the total number of families in this sample.

In summary, the children represented in this study were severely neurologically impaired with complex medical conditions and nursing needs which severely limited their growth and development and even threatened their lives. The children began experiencing symptoms of their medically fragile conditions at birth or within the first 3 months of life, except for one child who had an accident before age 2. One-half of the number of children were diagnosed within a week of their births; all were diagnosed before their second birthdays. All the children in this sample received 24-hour nursing care at home for a period of time before their admission to a pediatric skilled nursing facility, many for several years.

Sample Characteristics of Parents

Parents of 16 children participated in interviews for this study: 16 mothers, 6 biological fathers, and 1 step-father, for a total of 23 parent participants. The 32 biological and 2 step-parents in these families ranged in age from 23 to 51 years ($N = 34$; $M = 40.35$; $SD = 6.83$).

All parents identified themselves as Caucasian. After listening to the list of ethnic groups, seven parents additionally identified themselves or the child's other parent as having Native American lineage, ranging from "some" to one-half. No other ethnic groups were represented.

Table 3 depicts the educational levels for 32 biological parents and 2 step-parents. All of the mothers and nearly all fathers were high school graduates or the equivalent; most of the parents had at least some college and 50% were college graduates or had graduate degrees. Their educational abilities suggest that they had the intellectual resources to learn the skilled nursing tasks necessary to care for their children at home, to cope with the intricacies of health care systems, and to form experience-based opinions about health care organizations.

Table 3

Parents' Educational Levels

	Parents			
	Mothers (*n* = 16)		Fathers (*n* = 18)	
Educational Level	*n*	*P*	*n*	*P*
High School Incomplete	0	0.00	1	5.56
GED	0	0.00	2	11.11
High School Graduate	6	37.50	3	16.67
Some College	2	12.50	3	16.67
College Graduate	7	43.75	5	27.78
Graduate Degree	1	6.25	4	22.22

Five mothers identified themselves as homemakers; four worked in the food service industry; three were in education as teachers or aides; three were in health care or social services; and one was an artist. Four fathers worked in the trucking industry; three held technical or clerical positions; three worked in the food service industry; two were in sales and marketing; two were in construction work; one was a health care provider; one was in law; and the occupations of two fathers were unknown.

Five parents (31%) were single mothers. Eleven parents (69%) were currently married; of those, two mothers had remarried following divorce and 3 to 4 years of single-parenting their medically fragile children at home. The number of years of marriage ranged from 1 to 26 years (*N* = 17 [15 original marriages; 2 remarriages]; *M* = 12.41; *SD* = 8.08).

Because of this study's focus on organizations, parents were asked about their experiences with any type of formal organization in roles such as volunteers or advisory or governing board members. Table 4 summarizes those data.

Table 4

Experience of Parents in Other Roles with Formal Organizations

	Parents			
	Mothers (*n* = 16)		Fathers (*n* = 18)	
Formal Experience	*n*	*P*	*n*	*P*
None	6	37.50	4	22.22
Minimal	4	25.00	3	16.67
Moderate	4	25.00	4	22.22
Extensive	2	12.50	2	11.11
Unknown	0	0.00	5	27.78

Note. The number of fathers includes two step-fathers.

In summary, the parents participating in this study were Caucasians of mature age and often employed outside the home. They were well-educated: 100% of the mothers and 84% of the fathers graduated from high school; 62% of the mothers and 67% of the fathers had at least some college. All of the 16 mothers and 7 fathers or step-fathers participated in the study. More than half (*N* = 9) of the children's parents were still married to each other.

Characteristics of Families

In addition to the medically fragile child, most parents had other children who needed their time, attention, love, and care. The number of siblings in the family home when the medically fragile child lived there is summarized in Table 5. In addition, two children had half-siblings living in another parent's home.

Table 5

Number of Siblings in Family Home During Child's Residence

Number of Siblings	Number of Families	*P*
None	3	18.75
1	4	25.00
2	6	37.50
3	2	12.50
4	1	6.25

Medically fragile children are born into families with ranges of financial resources and sizes. Table 6 depicts the annual household incomes and the number of family members in the home, exclusive of the child receiving nursing home care, for the 16 families represented in the study.

Table 6

Annual Household Income and Family Size

Annual Household Income	Families (*n*)	*P*	Family Members (*n*)
<$11,000	2	12.50	1
$11,000 - 20,999	1	6.25	2
$21,000 - 49,999	8	50.00	1-5
$50,000 +	5	31.25	4-6

One-way distances between the parents' homes and the children's facilities ranged from 3 miles to 180 miles (*N* = 20; *M* = 28.56; *SD* = 45.02). Distances were included for four divorced fathers who regularly visited their children in their facilities. One-way driving time for families at the greatest distances (125 miles and 180 miles) were 2 hours of freeway driving and 3 hours of non-freeway driving, respectively. Distance from the facilities made visiting challenging, particularly when traveling with siblings; however, families in this study who lived at greater distances made the trip regularly and reported frustration at not being able to visit more often. Families living in the metropolitan area also visited regularly, with varying degrees of frequency.

In summary, most families (*N* = 13) had other children in addition to the medically fragile child in care. Most (*N* = 13) were of moderate income. All but three families lived within the tri-county metropolitan area in which the facilities were located.

Data Collection

Qualitative data were collected in two stages. First, parents of children receiving care in any of the three pediatric skilled nursing facilities were interviewed as individual families. Second, these parents, as they were willing and available, participated in focus group interviews. There was a sufficient number of parents who were willing and available for the focus groups. Therefore, all parents who were included in the focus group interviews also had participated in the initial individual interview.

Individual Interviews

The purpose of interviewing parents first as individual families was to capture their experiences and to do so without their being influenced by other parents' comments. Pediatric skilled nursing facilities are scarce and precious resources and it was expected that some parents might be reluctant to express negative experiences in the presence of others. The format was selected in order to free parents to relate their experiences initially without the constraints of other parents' perceptions. In addition, because perceptions of organizational effectiveness can change over time, it was important to gather accounts of parents' own experiences before they were exposed to other families' expectations. For this study, this format was most likely to promote parents' communication of what they experienced and what meaning they gave it.

The researcher developed and used an interview guide to elicit parents' descriptions of their experiences with the organization caring for their child (Appendix B). The interview guide was based on a review of the literature, discussions with professionals in family nursing and organizational theory, and the researcher's more than three decades' experience with medically fragile children and their families. The researcher used the framework of an open systems model. Open-ended questions were developed that corresponded to aspects of open systems: context, inputs, transformations, outputs, and feedback effects. Interview questions related to indicators of the organization's inputs included experiences with the child's admission; parents' perceptions of the sufficiency of resources, such as staff, funding, donations, equipment, and supplies; and their perceptions of the facility's responses to environmental change, such as responses to changes in regulations. Interview questions related to indicators of transformations or internal processes included parents' experiences with decision-making, support, communication, the organization's sense of its identity, its adaptability, problem-solving, and team spirit. Output indicators included goal attainment, parents' perceptions of the facility's sense of its mission, parent satisfaction, and parents' sense of employee satisfaction. Interview questions related to feedback effects included parents' experience giving feedback to the facility, ideas for ongoing feedback, their experience of the facility as open (or not) to new ideas, their advice to other parents, and their advice to the facility for its improvement. The interview guide also included probes to help draw forth the parents' values and expectations of facility care and the context of their relationship with the facility. A final question was included as a means of validating the inclusiveness of the interview guide.

Focus Group Interviews

There were two purposes for the focus group interviews: establishing credibility for the descriptive themes of the study and collecting additional data. Parents were asked to construct an ideal pediatric skilled nursing organization from the consumers' perspective. In addition, they were asked to respond to a question regarding concepts of parent satisfaction, comfort with care, and possible changes over time.

For the data collection portion of the focus group interview, the researcher developed and used a worksheet. The worksheet focused on the features parents considered most important in areas related to the facility's environment, program of care, and the organization providing care (Appendix C).

Demographic Data

In addition to qualitative data gathered in the two types of semi-structured interviews, the researcher requested demographic data (Appendix D). These data assisted in the construction of thick description of the families' context.

Procedure

Overall

One couple whose child was in care in one of the pediatric skilled nursing facilities participated in a pilot interview to refine the interview guide. The researcher reviewed her interview techniques and made necessary modifications, then carried out the initial family interviews with the sample parents.

At the beginning of each individual and focus group interview, the researcher explained its purpose again. In addition, she reminded parents that the study was intended to elicit their experiences, and was not an evaluation of their specific facilities. The researcher assured parents of confidentiality to the greatest degree possible, and explained what she would do to safeguard it. Parents were asked to use first names only while the interviews were taped.

The researcher tape recorded all interviews and made written notes during and following each interview. Tape recordings of the interviews preserved the words in the order they were spoken. The tapes were professionally transcribed. The handwritten notes made during and immediately following each interview facilitated the preservation of respondents' gestures and body movements and helped interpret the spoken word. Using Sandelowski's (1995) suggestions, the researcher made reflective memos of thoughts and impressions about the interviews as data were prepared for analysis and relevant literature again was reviewed. Data from the tape recordings and transcriptions, interview notes, field notes, and reflective memos all were included in data analysis.

Individual Interviews

The individual parent interviews took place in the location of the parents' choice, either the family home ($n = 8$) or at the child's facility ($n = 7$); one took place at the father's office. The researcher reminded parents that the interview would likely take about 2 hours, but assured them that she would take as much time as they liked. The length of time for the individual interviews ranged from 1½ to 3½ hours and averaged 3 hours. After reviewing the purpose of the individual interviews and the subsequent focus group interviews, the researcher gave parents a consent form (Appendix E) which they were asked to read, seek clarification if they had questions, and sign. The consent form included space to indicate whether the parents were willing to participate in the subsequent focus group interviews. All but three parents indicated interest in the focus group interviews.

Individual interviews of the parents of the 16 children resulted in 432 pages of transcripts. During each interview, the researcher took notes on a 5-page focused interview guide form. After discussing the items on the individual interview guide, the researcher completed a 3-page demographic information form for each family. At the end of the interview session, the researcher again reviewed the purpose of the focus group interviews and invited parents to reflect on their responses during the time interval before then.

Focus Group Interviews

The individual and the focus group interviews took place 4 months apart. The researcher telephoned all parents who participated in the individual interviews to assess their willingness to participate in a focus group interview and to coordinate schedules. Of the three parents who originally had indicated willingness to participate only in the first interview, two indicated interest in participating in a focus group but were unable to due to personal circumstances; one parent could not be reached. The researcher mailed a Focus Group Work Sheet (Appendix (C) to the parents who agreed to participate, asked them to complete it prior to the gathering, and to bring it with them to use during the discussion.

The number of focus group interviews that was conducted depended on the final total and composition of participants. Groups had to be small enough so that all persons could participate, yet large enough so that a range of viewpoints could be shared. Typical focus groups range from 7 to 10 (Krueger, 1988). Due to attrition, 18 parents formed 3 groups of 5 to 7 each. For this study, couples were in the same group. Had anyone expressed a different preference, the request would have been accommodated. Each group was composed of a mix assuring representation of the three length-of-stay categories. Each group consisted of a mix of parents whose children were in different facilities, to enhance the realization that the data were gathered at different sites and to preserve confidentiality. The three focus groups, comprised of parents, the researcher, and an individual who assisted with recording the discussions, met in an available location unrelated to any of the families or facilities because of space requirements. The length of time for the focus group interviews ranged from 2 to 3½ hours and averaged 3 hours. All parents participating in the focus group interviews had signed a consent form covering both individual and focus group interviews (Appendix E).

For the data collection portion of the focus group interviews, the researcher asked the parents in the group to share in turn their five most important features in the first category, the facility's environment. When each person had an opportunity to express his/her most important features, that category was opened for discussion and further ideas. The second and third categories, the facility's program of care and the organization providing the care, were discussed in turn.

While parents shared their ideas, the recorder wrote them on newsprint sheets, which were posted around the room. Parents were then given five adhesive dots for each category, to indicate on the newsprint sheets their final most important features.

Later during the focus group meetings, parents were asked to respond to questions regarding parent satisfaction. These questions were expanded from one asked during the individual interviews. The questions were, "What has been your experience of satisfaction in your child's pediatric skilled nursing facility? Have you experienced a change in your overall comfort or satisfaction over time? Was it in 'comfort' or 'satisfaction'? Is there a difference? Which direction was it as time went on, more or less?"

The three focus group interview sessions produced 70 pages of transcripts. Parents' focus group work sheets, the researcher's notes, and newsprint sheet notes taken during these discussions provided almost 40 pages of additional data. In summary, with the data from the individual interviews, the results of this study were based on analysis of nearly 700 pages of written data. Because parents' perspectives in the focus group sessions were very similar to those they expressed in the individual interviews, their comments have been combined in the results.

Data Analysis

Qualitative Analysis

Qualitative analysis is a method that combines qualitative content analysis and the researcher's own experience in a process which is summarized as follows:

1. Transcribe each interview;
2. Review each transcript for significant themes;
3. Develop codes and definitions for themes;
4. Establish intrarater agreement;
5. Establish interrater agreement;
6. Using original transcripts, refine codes and definitions.

This blending of methodological features is supported by Patton (1990) in his discussion of methodological triangulation, that is, borrowing and combining desired parts of pure methodologies as a way of strengthening research design.

Qualitative analysis was selected because this method allowed the researcher to invoke her knowledge of families of medically fragile, severely neurologically impaired children and of organizations in order to focus on the phenomena of this research. Parents' stories of their experiences with the facilities caring for their children included, by their nature, highly emotional, extensive, and complex narratives of the circumstances surrounding their children's illnesses and disabling conditions. Qualitative analysis assisted the researcher in balancing the parents' needs to relate extensive stories, the researcher's interest in their stories and the need for thick description, and the focus on the phenomena of interest for this study. This balance was approached through directing parents' responses to interview questions based on pre-set code categories.

Coding Framework

This study focused on parents' experiences of organizational effectiveness, and considered parents to be key constituents of the organization. Constituents' values and expectations shape their perspectives of the organization. The coding framework used included questions around accepted functions of an open organizational system: inputs, transformations, outputs, and feedback effects; and the parents' values, hopes, and expectations regarding the organization. The researcher analyzed these data to discover the themes that emerged around that framework and to determine the relevance of the themes to the research questions.

Codes and Themes

The researcher used two sets of codes: pre-established and emergent. Pre-established codes allowed the researcher to use her own experience with organizations to guide the data analysis for content related to organizational theory. Emergent codes allowed the researcher to analyze parents' experiences of pediatric skilled nursing facilities as told in their own words. The results of both analyses linked theoretical and experiential concepts, and provided rich information for answering the research questions.

Pre-established Codes

The researcher developed pre-established codes (Appendix F) related to the four research questions, including elements of open system organizations, elements of family-centered care, factors affecting parent satisfaction, and elements of parents' perceptions of ideal pediatric skilled nursing facilities. Transcripts of the 16 individual parent interviews and the 3 focus group interviews were studied multiple times and analyzed for content related to these codes.

Emergent Codes

As the transcripts of the individual and focus group interviews were studied and the researcher "lived in the data," patterns of experiences common to parent participants emerged. The researcher attempted to understand parents' meanings in the contexts of their responses. The experience patterns were categorized into descriptive themes. These themes were reviewed and refined with members of the dissertation committee, other qualitative researchers, and other individuals familiar with long-term care and the families of medically fragile children.

Answering the Research Questions

The first part of Research Question 1 was answered by a qualitative analysis of pre-established and emergent codes from parents' responses throughout the individual and group interviews. The codes were organized into themes based on parents' descriptions of their experiences. Each transcript was reviewed for significant themes, using the coding framework of an open organizational system of inputs, transformations, outputs, and feedback effects in a broad situational context.

The first part of Research Question 2 was answered using qualitative analysis with the data provided in all individual and group interviews. The second part of Research Question 2 was answered by analyzing the transcripts of all individual and group interviews, comparing parents' descriptions to pre-existing codes of the accepted elements of family-centered care. The third part of Research Question 2 was answered by analysis of the data from individual and group interviews, focusing on the values parents attributed to key experiences.

Research Question 3 was answered using qualitative analysis to examine parents' responses to questions regarding their experiences of satisfaction. The analysis involved scrutiny of parental responses during the entirety of both interviews, focusing on identification of factors affecting parents' satisfaction with care.

Research Question 4 was answered using qualitative analysis to summarize the data of parents' contributions primarily in the three focus group interviews. Parents' individual interviews were also analyzed to answer this question; however, the focus group interviews were the major sources of the data.

Credibility, Auditability, and Fittingness

The criteria for credibility, auditability, and fittingness proposed by Lincoln and Guba (1981) as appropriate for judging scientific rigor of qualitative studies and assuring confirmability were met by several strategies. These strategies included the use of focus group interviews, setting aside the researcher's preconceived expectations, experts' review of the findings, thorough documentation, review by the research committee, and thick description.

Focus Groups

One of the two purposes of the focus group interviews was a method for validation of the description of themes of the study (Streubert, 1991). The representation of the parents' experiences of organizational effectiveness or ineffectiveness were judged by parents in three focus groups. Parents were asked to respond to the themes generated from the data of the individual interviews and to augment or refine them based on their experience. The researcher used an interview guide (Appendix G) which incorporated themes derived from the data from the individual interviews. The guide was developed during the course of the study as themes emerged from the initial data.

Other Means

Additional means of establishing credibility were used. In order to safeguard the truth value of the study, the researcher consciously and conscientiously set aside her own experience and expectations to listen carefully to the parents' narratives (Sandelowski, 1986). In addition, two qualitative researchers, a nurse with expertise in long-term care and a nurse with extensive experience working with medically fragile children and their families were asked to review and critique the findings.

Auditability

The researcher maintained careful documentation of paper and tape recorded raw data, impressions, reflections, and analysis decisions. Steps in the research process were discussed regularly with the research chair and committee. There was ample information for an independent researcher to trace the research process from the research questions and raw data through the analysis and interpretation of findings.

Fittingness

The researcher provided thick descriptions of the respondents' accounts and their backgrounds. This allowed others to determine whether the findings fit the data and whether the findings were relevant for their own practice, research, and theory development.

Protection of Human Subjects

The investigator followed all guidelines of Oregon Health Sciences University's Institutional Review Board regarding protection of human subjects. The investigator reviewed the purpose of the study and the assurance of confidentiality with all parents at both individual and focus group interviews, and obtained their written consent to participate. Subjects directed the investigator regarding the degree of information sharing in which they wished to participate.

Individual and focus group interviews were audiotaped and professionally transcribed. Subjects' first names only were used during the interviews. Only the researcher and the professional transcriber saw the subjects' first names; following the first transcription, all names were eliminated and only code names and numbers were used. During and following the study, audiotapes and transcriptions were maintained in a locked file, accessible only to the investigator. Parents' names, addresses, and telephone numbers were maintained in a log separate from the audiotapes and transcriptions, in event of further analysis of the data.

The study results and discussion were written using substitute names for parent and child, in order to protect their confidentiality. Subjects were described in such a way as to safeguard against their being identified or linked with a particular facility, for example, by changing the gender of parent or child at times. Parents and the pediatric skilled nursing facilities caring for their children were provided an abstract of the completed study.

In summary, this was a descriptive, exploratory study of parents' experiences with the pediatric skilled nursing facilities caring for their children. A sample of 23 parents of medically fragile children were individually interviewed using an interview guide. Subsequently 18 of them participated in a focus group interview. Data were analyzed using phenomenological qualitative content analysis. The next chapter presents the results.

CHAPTER 4

RESULTS

The overall purpose of this study was to develop family-based measures of organizational effectiveness to evaluate organizational performance in pediatric skilled nursing facilities. The study was viewed as a first step toward developing a theory of organizational effectiveness to guide pediatric skilled nursing facilities. The researcher analyzed data from 16 individual and 3 focus group interviews using two sets of codes: pre-established, to guide analysis for content related to organizational theory; and emergent, to enhance understanding of the patterns of parents' experiences.

The community of children who are medically fragile and severely neurodevelopmentally impaired receiving care in local pediatric skilled nursing facilities, their families, and facility staff is relatively small and interrelated. Some families have received services at more than one facility; some staff have been employed at more than one facility. Key administrative staff know each other. In order to safeguard confidentiality to the highest degree feasible, identifying information was blended as much as possible while still providing the reader with adequate profiles of these families. Pseudonyms were used and genders were sometimes changed. Where available, data about biological fathers not participating in the study were included.

Parents' Descriptions of Their Experiences with Pediatric Skilled Nursing Facilities

The first research question was, "How do parents describe their experiences with the pediatric skilled nursing facilities caring for their children?" Through analysis and discussion, several themes emerged from the parents' descriptions of their experiences. One overarching theme, Contrasting Feelings; three major themes, Negotiating Complementary Care, Establishing Supportive Connections, and Getting My Life Back; and 16 subordinate themes were identified. These 20 themes describing parents' experience corresponded to the elements of an open organizational system, which was the framework used to develop the parental interview guide: inputs, transformations, outputs, and feedback effects in a broad situational context. Themes related to organizational inputs described parents' experiences with the circumstances of their children's admission to the facility and their interests, values, and hopes for the quality of care their children would receive. Themes related to organizational transformation described parents' experiences with the processes of care within the facility, such as problem-solving and decision-making. Themes related to organizational outputs recounted parents' experiences with such aspects as goal achievement and satisfaction. Themes related to feedback described parents' experiences with providing evaluative information or advice. The themes will be presented in the open organizational system framework.

Most of the parents' experiences captured by the identified themes fell into the organizational element related to internal processes, or transformations. It was this category which described parents' interactions with the pediatric skilled nursing facilities caring for their children. Parents' descriptions contained the answers to Research Question 1.

Inputs

Three codes were included in this section. They were: "I/We just couldn't do it anymore"; "The process of letting go"; and "The need to know my/our child will be cared for and about."

The open system element of inputs included parents' experiences which occurred primarily before the child entered the facility, the effects of which parents carried with them to their interactions with the facility. Parents described experiences that for some of them occurred as many as 15 years before the interview. Yet, their memories of those events were clear and sharp, and the surrounding emotions welled up again with the telling; nearly every parent was in tears at some point during the interviews. There were three themes that described parents' values, expectations, and realizations prior to their child's admission to the facility.

"I/We Just Couldn't Do it Anymore"

The code, "Couldn't do it anymore," was defined as parents' realization that they were exhausted, overwhelmed, and had depleted their resources for continuing to care for the child at home. Seeking a nursing facility for their child was a last resort. Several times the realization was precipitated by a family crisis or by the child's increasingly fragile condition. All parents in this study cared for their children at home for varying lengths of time, in contrast to parents whose children were transferred directly from an acute care hospital to a pediatric skilled nursing facility. Parents described the intense care they provided in the home and the struggles involved as they attempted to fulfill multiple roles including full-time nurse, respiratory therapist, pharmacist, dietitian, physical therapist, spouse, parent to this child as well as to siblings, cook, grocery shopper, launderer, housekeeper, and, for many, employee outside the family home. Some parents sought a variety of sources of possible assistance in order to continue providing care at home, but were unable to access adequate and appropriate help.

Parents also described difficulties accessing information about pediatric skilled nursing facilities. Most were eventually referred to the facility by a physician or a social worker.

By the time the children were admitted to their pediatric skilled nursing facilities, the families were physically and emotionally exhausted and often financially depleted as well. Parents described themselves as physically and emotionally absent from their other children, due to the care demands of the medically fragile child. Two parents gave these descriptions:

> We had our child home for nine months after his birth, and we were right at the end of our chain. You know, as a matter of fact, I don't know to this day that I've recovered from some of what I guess you'd call emotional damage that the hardship caused that we went through when we were with him at home. You know, [we] were at each other's throats and [our other child] was getting the short end of the stick too, because we were just so tired and worn out and all the machinery that he was hooked up to, I literally slept with one foot on the floor and one eye open. Just literally, I mean, until we just couldn't take it anymore.

> We couldn't actually make the decision. We just couldn't choose to do it until we burned out and saw our family going downhill. We never functioned as a family. . . . We just got burned out. We knew, but we had to get to the point where we couldn't do it anymore before we could make the decision.

"The Process of Letting Go"

The code, "Letting go," was defined as the parents' sense of having to relinquish many things they held dear: their child; a dream; "perfect" care; making all the decisions they had been making for their child and which they had the right and responsibility to make. "Letting Go," a psychological process, seemed to occur as a necessary prelude to the more deliberate physical act of turning over the child's care. One parent described letting go this way:

> I know as time went by that dream probably kind of flickered out. You really began to realize that Ingrid wasn't going to make any gigantic leaps in terms of her development so it became more of a quality of life for her. And health issues because she had profound, on-going health problems.

"Need to Know My Child Would Be Cared for and Cared About"

The code, "Cared for; cared about," was defined as parents' primary concern that their child would receive good nursing and medical care, therapies and activities, but would also be loved as they loved the child. The concern that nobody else could know their child as well as they did, provide the same quality of care they did, or love them as they did delayed the search for residential placement for several families. One parent explained that she wanted:

> Good medical care, first of all, because that was my focus. I wanted to make sure somebody could do that part of it. Good nursing, I mean, you know, we wanted to have a good feel for the quality of the nursing and the number . . . It was real important to me that people give him a lot of attention and love.

In summary, parents who provided complex nursing care at home prior to their children's admissions to pediatric skilled nursing facilities shared common experiences. They came to the realization that they could no longer carry on; they prepared to transfer the child's care to others and to alter their roles in that care; and they identified the characteristics they sought in the new caregivers.

Transformations

Twelve codes were included in this section. They were: "Turning over"; "Part of our family"; "Changing parental role"; "Guilt and worry: Constant companions"; "Perpetual vigilance"; "Control"; "Trust"; "My way"; "Feeling welcomed"; "Being judged"; "Masking feelings"; and "Feelings of isolation."

"Turning Over"

The code, "Turning over," was defined as parents' actively and intentionally entrusting the physical custody of their children and their 24-hour care to the facility. Parents described their decisions and the experience of admitting their child as: "overwhelming"; "unbearable"; "gut-wrenching"; "terrible"; "crushing"; "stressful"; "devastating"; "a horrible necessity"; "like giving our child away"; "like a death"; "like the end of the world." "The decision to admit our child was the hardest one of our lives." And, for most parents, it was a relief. One parent remembered,

> I think putting her in a facility was just absolutely gut-wrenching. I think it made me a little mad when people said, "Oh, it must be such a relief for you now." It was not a relief; it was terrible, especially when you have a child so impaired that you spend all those years reading their signals and knowing what they like and what they don't like. They can't tell somebody. Just turning her over to even caring people was devastating.

For most parents, the mechanics of the actual admission process went smoothly. They appreciated nurses who seemed knowledgeable and competent, and who welcomed and encouraged their input and involvement in developing the child's plan of care. They felt comforted when nurses told them they could stay as long as they liked and encouraged them to call whenever they had questions or simply wondered how their child was doing. They found it helpful when the facility sent forms ahead of the admission for parents to complete information about such things as the child's condition, diet, medications, favorite positions, likes and dislikes, favorite toys, sleeping habits, and so on. Parents expressed gratitude for most staff members' attitudes, and especially mentioned social workers' empathy, gentleness, understanding, and "cutting through red tape."

Dealing with the child's personal belongings seemed to have significant emotional impact for several parents, who described the unbearable ordeal of packing the child's belongings knowing the child would not be coming back home, or of divesting of them later. It was comforting to parents to be able to settle their children into the assigned room; a couple of parents found it offensive and hurtful when a facility staff member took over marking the child's belongings and putting them away. Some parents described their dismay with the facility's later misplacing their child's personal belongings, for example, the special Christmas blanket from Grandmother later found in the common linen cupboard; coordinated clothing sets separated and misplaced; their child's carefully selected toys scattered in the common activity areas.

Many parents described sibling responses to the child's admission; some tender, some troubling. One sibling insisted on carrying the child's suitcase to the facility and wouldn't let anyone else do it. Some siblings verbalized their worries that they might also be put someplace else if they got sick. As one parent explained,

> When we first put Olivia there, Owen couldn't understand why we did that, and he thought we were going to put him in a home, too, and we had to explain to him that, you know, that he knew Olivia was medically ill and stuff and that's why she had to go in there for better help.

"Our Child Is Still Part of Our Family"

The code, "Part of our family," was defined as parents' determination and efforts to maintain their children as part of their families despite out-of-home residence. Parents' efforts included frequent visits; including siblings in visits; personalizing the child's living space with family photos, greeting cards, posters, and seasonal decorations; daytime excursions out of the facility; overnight visits home; and participating in family-oriented activities organized by the facility.

Parents considered it important to promote a sense of family and to maintain a relationship with the child in care for themselves, their other children, grandparents, and other extended family members. However, nearly all families described difficulties with visiting. Distances could be daunting. The available visiting spaces were not comfortable for most families. Many families expressed the need to be in a private place with their child, rather than in active, busy, more visible public spaces. Families wanted to be able to visit in a room where they could gather to enjoy an activity such as a video together, without worrying whether siblings were disrupting the unit. They wanted rooms designated and available for family visiting only, and not used for other purposes such as staff meetings or storage.

Parents described difficulties with sibling visiting. Young children usually enjoyed visiting and the facilities seemed to have appropriate toys available for that age level. However, by age 8 to 10 years, siblings outgrew the age levels of the available toys, tended to be more active and noisy, and were sometimes regarded by the staff as disruptive. As siblings entered their pre-teens and teenage years, they typically became embarrassed and reluctant to interact with the child in care. They became bored, restless, and uncomfortable with little to do. They resisted coming to visit. While a couple of parents thought that families should deal with siblings themselves, most other parents felt that it would be helpful for the facilities to have a working TV and VCR available with a collection of movie videos and video games in the family visiting room. In addition, many parents thought it would be helpful to have anticipatory guidance about siblings' developmental milestones, as well as support groups for siblings themselves to assist them with their changes related to the child.

Most parents expressed appreciation for facility-sponsored family activities, such as Christmas parties, Thanksgiving dinner, and group outings as a means of family connections. However, these activities can be difficult for some families to participate in due to distances and work schedules. Many families thought it would be helpful for the facilities to offer a greater number of such activities at a greater variety of days and times, including evenings and weekends, to increase the possibilities of better participation.

For some families, the only time they felt whole as a family was when all members were together in the home, either for the day or overnight. Families, including those from out of town, were encouraged to take their children for outings. Yet, as their medically fragile children grew older and larger, they become more difficult to transport. Few families had special vehicles for the disabled, because their child no longer lived with them. Several families expressed the desire that a facility van with a hydraulic lift could be made available for their use for outings and to make home visits more possible. A parent expressed it this way:

> It would be so nice if there was a facility vehicle [to use]. If we wanted to have our child come home, we have no way. We don't have any way to transport our child when we come here. It would be nice to be able to go out somewhere in Portland. And when we talk about having family time with your child, the only kind of family time I can have is in my own home. I don't feel family when I'm here. It just doesn't work; it's not normal. You

> want her under normal circumstances. You just want her to be there, doing the regular stuff. Everybody acts differently here.

"My Parental Role Changed"

The code, "Changing parental role," was defined as parents' experiences with altered roles or expectations because of their child's being in a care facility. Parents described their struggles transitioning from the persons "in charge" to participants and sometimes even observers. Some parents felt that they were viewed differently by their friends and relatives following the child's admission. Not all facility staff seemed understanding about these role changes. Parents found it helpful when staff assured them that they were not relinquishing their parental rights, that they were not giving their children away, and that they were still "Mom and Dad." Two parents expressed the process in this way:

> I just think I learned that the relationship changed, that it had to change. The role I was playing, the letting go, the tearing apart process. Still having that gut feeling and knowing in my heart that that's my baby. He's a part of me. He's my child still, but the relationship is different. It took time for me to accept that the relationship is okay to change. I wasn't sure it was okay to do that. Part of me wants to do this and part of me wants to let it go.

> You're changing your whole perspective of yourself. You've been this [parent] full-time. You know everything about your child and you're the only

> one who can take care of her the way she should be and then all of a sudden, that's totally gone and your whole role in society has totally changed. That's kind of a schizophrenic type of situation to be in.

"Guilt and Worry Are Constant Companions"

The code, "Guilt and worry," was defined as parents' ceaseless worry about their child's well-being and feeling guilty that they might not be doing enough to assure optimum care. This pattern was pervasive, and occurred while the child was cared for at home and later in the facility. Parents worried about the continued availability of their child's facility. As children grew into their pre-teen and teenage years, often in spite of earlier physician predictions of a much shorter life span, parents began worrying about the availability of an appropriate, safe facility for them as young adults. From the parents' stories, there was no indication that facility staff had awareness of this burden that parents carried. A parent explained,

> When I would wake in the morning, my eyes would open and the first thing I would think of was Harrison. . . . So from the minute you open your eyes, there was a sense of guilt or worry. It was like if you took time for yourself, that was somewhat like taking time away from him. . . . I felt like there was always something that had to be done. . . . He was so needy. . . . So that was my constant companion, guilt and worry.

"Parenting My Child Means Perpetual Vigilance"

The code, "Perpetual vigilance," was defined as parents' ongoing sense of responsibility for assuring the best care possible for their child and intervening when necessary. Although their children were in a 24-hour nursing facility with staff they trusted to varying degrees, parents described feeling this sense of responsibility. A few parents described their need to be particularly vigilant; others were watchful at more of a distance. All, however, described some degree of ongoing attentiveness to their child's quality of care. Two parents gave this description:

> He had a respiratory illness and I started noticing that the steroid medication they usually had to give him to get him through an episode, that he was still showing the side effects long after he should have been. And I zeroed in on what's going on with the patient care manager. And come to find out, because I had asked, I finally find out that the pediatrician was going to wean him off the phenobarb. I said, "Huh-uh [no]. We don't do this. You don't know what I've gone through with him before." And because I expressed my concern, they were great about it. The nurse talked to the doctor . . . let him know my concerns, that I was not for this idea at all. And they put him back on it and he's done better. But it caused me some worry.

> Each and every time a new caregiver comes into the picture we spend a lot of time giving that caregiver information that's specific about Freddie. We try

> not to overwhelm them because if you try to do it all at once none of it will stick and it will just overwhelm them with detail. So we try over a period of a month or 2 months to feed them information and to reinforce the most important information with them. For something like a fever, at some point they would give him Tylenol. What we would hope would happen would be more on the order of looking for signs of discomfort, say checking for a rash. To look for the cause. Trying to pinpoint, you know, what's going on with this? Often with a fever there's going to be more than the fever, and to try to sit down and see, does he act like he has a sore throat, does he seem to be achy, is he holding still, does he look like he might be nauseated. Try to sift down and get more information. And that's a frustration, that they tend to not look for the cause of symptoms, or put things together to see a pattern. . . . If there's obvious problems, and we have walked in at a point where we're the only ones intervening in a process where the intervention should have come long before we got there, that is an anxious time for us. We tend to then hurl ourselves into the breach to fix whatever it is or put it to rights or stabilize the situation. And that has happened. It's more likely to happen with strangers who come in, who are not familiar with Freddie.

Inadequate staffing, staff assignments, staff turnover, and the use of agency staff were mentioned by nearly every parent participant in the individual interviews and included patients at all three facilities. Parents viewed these situations as negatively affecting the quality of their children's care in the extreme. They described instances in which there were insufficient numbers of direct care staff to assure that their children received safe and competent care, and times when regular staff's patient assignments were rotated in such a way that they were unfamiliar with the children for whom they cared. Parents expressed deep concerns about what they regarded as inadequate orientation for new staff and believed that newly hired or agency staff were assigned direct patient care when they were as yet unfamiliar with the idiosyncracies of each child and therefore unable to provide safe and competent, much less loving, care.

Parents introduced topics related to problems with inadequate and unfamiliar staff at each of the three focus group meetings held as part of this study. There were animated discussions at each meeting. When participating parents were invited to indicate their top priority subjects on newsprint flip charts, these issues received many marks. Parents wanted the facilities' administrations to commit to "better pay, better benefits, and better working conditions" as means of "recruiting, hiring, training, and retaining" adequate numbers of good quality staff. Staffing problems affected not only the parents' perceptions of their children's quality of care but they also influenced parents' levels of worry and affected their trust, comfort, peace of mind, and satisfaction.

While parents were deeply concerned about inadequate or inexperienced staff within both individual and focus group interviews, parents expressed their understanding of and appreciation for the staff's hard work. They questioned whether the staff realized the parents' gratitude, and proposed that facilities should plan various rewards and activities for the staff's benefit. Two parents offered the following thoughts about staff:

> I'm sure they would like to get paid more for the hard work they do and I do feel like they work very hard. I'd like to see [the facility] do more things with their employees like they used to. They used to have potlucks, things to give the employees a real good attitude. To encourage them what a good job they're doing. Kind of a reward, something to look forward to . . . parties . . . summer barbecue . . . something fun to do because they do an awful lot of hard work. I just think the employees should be shown a lot of appreciation.

> I have sympathy for staff who work with kids like this because there are great rewards and then there are no rewards; I mean both . . . Just like we put so much into the children and not always get responses back from them, like you know, with Freddie, he doesn't smile, he doesn't say thank you for what . . . You know, you do all this work for somebody who doesn't even smile at them? That's really tough.

"Need for Control"

The code, "control," was defined as parents' sense of having or not having power, influence, or guidance authority regarding a decision or activity for their child. Parents described wide variations in the degree of participatory and vicarious control they exercised when their child was in the nursing facility.

When asked how decisions were made about their child, several parents described their active participation in major decisions, such as changes of seizure medication, and their delegation of minor decisions to the facility staff who kept them informed about such things as treatment of colds and sore throats. A couple of parents stated that they were the ones who made the decisions, and that the staff implemented them. One parent related that the facility telephoned her ahead for anything that required a signature as well as for major changes; otherwise the staff informed her after the fact. For the most part, parents spoke very positively about facility-initiated communication by phone, mail, and in person, and the facilities' responsiveness to parent-initiated interchanges. They believed that this flow of communication provided both themselves and the facilities with information necessary for them to make informed decisions regarding the children. Parents often mentioned attending regular multidisciplinary care plan meetings and Individual Education Plan meetings with the local school district staff as means of participating in decisions about their child. Many parents who were comfortable with their decision-making processes attended the planning meetings only when they had particular issues to discuss. A parent described,

> They always call us before any changes in her medication. They're really good. If I want changes then I call them with concerns. And they always take

> care of them. I get a call back. I didn't get to go to her care meeting this time and I had a concern, so the therapist called and talked to me about that. . . . I feel they're real open to suggestions. . . . They're always trying to push us forward for what we want for her. And they're there to offer whatever.

At least initially, however, other parents' experiences were not so positive. Some parents related that they had gone to considerable efforts over a period of time to get the facility nurses to include them in decisions regarding their child. They felt that the staff had seemed unused to parents wanting to have a degree of control about their children's care. However, at the time of the interview, for most parents previous conflicts were viewed as having improved over the years.

One parent related deep distress when feeling impelled to disagree with the facility staff about their proposed goals and programs for the child. Because disagreement was very hard, this parent voiced opinions only when forced to by the situation.

Some parents related that they rarely, if ever, had opportunities to exchange ideas or information with their child's pediatrician. They expressed the desire to participate periodically in a medical review of their children during the physician's visit.

"Trust"

The code, "Trust," was defined as parents' confidence in the facility staff, usually developing over time. Many parents recounted examples of their growing trust of the facility and its staff over periods of time. When parents perceived that their children were medically stable, doing well, and comfortable, they gradually developed confidence in the facility's abilities. Parents related that, in general, their anxieties decreased as they experienced greater confidence in the facility's competency. Enjoyment of reduced anxiety and greater trust could easily waver, however, by the introduction of inexperienced staff unfamiliar with their child. Parents' anxieties increased and the trust-building cycle had to begin again. One parent described the trust-building process in this way:

> With time you get secure. You know, it takes time to come to that point. It's a slow process, long and slow. You build trust with the staff, and friendships. . . . It took me a long time to trust that they really do care about the children. . . . A lot of it has been trust on my part, with time trusting things will get taken care of. . . . Now I trust the nurses' judgment. At first, I didn't trust anybody. . . . Now I'm not worried and when I do feel concerns, I talk to the nurses and it's taken care of. . . . When she first came in, I didn't trust very well. I didn't take people's word for it. I wasn't used to having support or help.

"The Facility Can't Do Everything My Way"

The code, "My way," was defined as parents' adaptation to the realization that the facility might not be able to do things "their" way. This often occurred as parents experienced the interactions within the facility and began to appreciate the numbers of children in care. It was a necessary reality even though the staff might wish to observe each family's preferences. One parent expressed it this way: "Your expectations may become more realistic. You realize they can't re-create your home. You would go crazy. If you couldn't achieve that, you would be insane all the time, worrying that they weren't being well taken care of."

"We Need to Feel Welcomed"

The code, "Welcomed," was defined as the experience of parents and family members being willingly included and being greeted hospitably. Parents described several experiences in which they and their family members felt greeted hospitably and included by the facility staff, and in which they did not. When parents felt that there was no welcoming attitude on the part of the facility staff or when staff did not convey the idea they were glad family members were there, families often felt as if they were merely visitors or even intruders. Parents felt as if their presence, or that of siblings or extended family members, was an inconvenience to the staff. It was important to many parents that they be greeted by name, especially when their children had been in the facility for several years. Many parents related how difficult it seemed to be for extended family members to visit in the facility; parents were particularly upset when older siblings or extended family members visited the child alone and were not greeted warmly.

Several parents mentioned their own embarrassment when they did not know staff members by name. They expressed the wish for some means of communication, such as an in-house newsletter, which would provide parents with a roster of staff names and photos, staff changes, and a schedule of future activities.

Some parents distinguished between meaningful inquiries about how they were doing and superficial, merely polite questions made in passing. They found it helpful when staff persons engaged them in significant explorations about how things were going for them and the rest of the family, and made suggestions for appropriate resources when indicated.

Several parents found it helpful when facility staff conveyed the idea that they enthusiastically welcomed the parents' interest and contributions regarding plans and decisions for the children's care. They appreciated receiving timely invitations to participate in care planning conferences, and having their schedules considered before dates and times were decided. Parents described welcoming issues in the following way:

> I think for facilities to make parents feel like they're welcome, they're wanted, you know, they want you to have involvement with the kids. Not making them feel that they are in the way or that they are bothering or disrupting the area, the environment. . . . That would have helped me more, to make me know that I wasn't just a bother. I always felt like I was a bother when I came up, and made noise and disrupted their quiet area, quiet time, or whatever. Allowing them plenty of private time. Offering a little more of: "Is

> there anything I can do? Is there anything we can do?" . . . Maybe offering more activities and inviting parents to come for their fun time. It's hard.

> They always greet me when I go and they're very, very nice. They feel happy for the child when the parents come to visit. They don't mind having our teenagers come; they're very supportive. We can take anybody there. They love the dog.

"Perceptions of Being Judged as a Parent"

The code, "Being judged," was defined as parents' feelings of being negatively evaluated. Several parents depicted instances in which they felt negatively evaluated by others, both in the facility and by society in general. They acknowledged the guilt feelings they carried with them, and the ease with which they felt bad about their children's situations. They felt particularly vulnerable to what they described as insensitive comments by facility staff, as well as by family, friends, and society in general. Some parents acknowledged that their feelings of being judged came from their own expectations of themselves as well as what they perceived as others' expectations of them related to such issues as frequency of visits and their children's residence in a care facility. Two parents explained their experiences this way:

> I went through phases where if I didn't visit Dale at certain times I wasn't sure I wasn't being judged. I didn't feel always that I was looked upon as a

good mother. I'm sure there was just a lot of just me in that, but remarks would be made, "Oh, I haven't seen you for such a long time" and I thought maybe just imposing self-guilt upon yourself because you haven't done what maybe you think you're supposed to do. So I would go home and try to work that out. But I think there were times when staff might not have been as sensitive to the things they might say to a parent. . . . I know they don't mean to throw salt at me but I'm already wounded and it just stings like heck. . . . Maybe it didn't mean a thing and maybe I took it that way. In fact, I would say I would avoid coming because I didn't want to. Then when I did because I was sure they thought I was this bad person. Because I was starting to let go and I didn't desire to be here as much. So if somebody said to me, "Gee, I haven't seen you for so long," I immediately thought, "Gee, you must think I'm real terrible." And then I would stay away even longer because I didn't want to be judged.

It was hard, first because I never thought I'd do that, to climb out of the idea that you're a mom and you're supposed to take care of the child. That was inside me, and I think you felt like other people thought that. People never said it about me, but they'd say things like, "I could never, if something happened to my child, I would never do that." At the same time, people

> would see Gretchen as just this little baby, and just not realize everything that went into taking good care of her.

"I Often Mask My True Feelings"

The code, "Masking feelings," was defined as parents concealing their true feelings, ideas, or opinions as a means of self-protection. Many parents described experiences in which they were careful to protect themselves by masking their real feelings, or their ideas and opinions. Some felt reluctant to risk exposure due to fear of crying in front of strangers. Some said that in addition to issues about the child in care, they had home and work situations that had them in turmoil. A couple of parents felt unfree to disagree with staff members' ideas unless the parent believed the decisions had serious ramifications for their child. According to these parents,

> It's just that it's very, very hard, and I don't think all the parents are the same. I think that the child, that the parents are going through different things with their child at different times and that different things are going on at home, and what may seem like something at face value may be altogether different.

> I think it's real important for the staff to be sensitive to the families. For instance, when I come, I may have been in a different place in my life and maybe it's inside me. . . . I wasn't real willing to share my feelings. So they

> have misread me, because I'm real good at that so I may not have let my feelings show.

"Feelings of Isolation"

The code, "Isolation," was defined as parents' sense of being bereft of understanding and support from others. Many parents described experiences of feeling isolated from others: their friends, relatives, society in general, and the facility staff. They related feelings of loneliness, with no one they felt they could talk to about their child: not only the problems but also the joys and the cute, child-like things they did. A couple of parents related that when they met people casually, they were in a quandary about what to say about how many children they had; they didn't want to burden a stranger with their story, yet they also did not want to deny their child's existence.

Following the initial period surrounding the child's admission, few parents had interactions they perceived as interest in, understanding of, or support of them personally by facility staff. There were few opportunities to interact with parents of other children in the facility who had similar experiences and were likely to be understanding, due to open visiting hours and reduced chances of encountering each other. Two parents expressed their experiences this way:

> I think the understanding of what it's like to be a parent in this kind of situation is really, really small. I don't feel like there's really anybody that's

> on our side, in that sense, of you know, that if we're having a hard time emotionally we could go cry on their shoulder; forget it. There's nobody.

> Once Gretchen was there, she's just kind of gone, 'cause your friends don't see her, and your children's friends don't see her. I don't think she seemed real to other people, and it was always hard for me to talk about it to other people.

In summary, transformations were internal processes in which parents experienced the pediatric skilled nursing facilities caring for their children. Parents turned over the physical custody of their children to the facility for care, experienced a welcoming atmosphere (or not), learned to maintain the child as part of their family, adapted to changing parental roles, dealt with constant guilt and worry, exercised ongoing vigilance about their child's well-being, realized the facility could not always do things their way, negotiated decision-making authority, and developed a degree of trust. Several parents also felt isolated, negatively judged by others, and, in interactions with facility staff, masked their true feelings to protect themselves.

Parents' Experience of Organizational Effectiveness

Research Question 2 consisted of three parts: "How do parents experience organizational effectiveness or ineffectiveness? More specifically, how do parents describe the family-centered care elements they experience in pediatric skilled nursing facilities? What do parents identify as the strengths and weaknesses of the facilities caring for their children?" Each part will be answered separately.

Organizational Effectiveness or Ineffectiveness

In order to answer the first part of this question, parents' descriptions from all individual and group interviews were analyzed. Three themes emerged from the data that corresponded to the open system component of outputs: "Negotiating complementary care"; "Establishing supportive connections"; and "Getting my life back."

Outputs

Outputs refers to organizational results such as goal attainment and achievement of constituent satisfaction. Three major themes, corresponding to conscious or unconscious parental aims, emerged from the data of parents' experiences. Successful realization of these aims led to parental satisfaction, which will be discussed in a later section.

"Negotiating complementary care". The code, "Negotiating complementary care," was defined as the forging of a mutually recognized, agreeable, satisfactory, and interactive working relationship between parents and facility staff in which both honor, seek, and appreciate the contributions of the other for implementing features of the child's care and for keeping each other informed. Parents described many experiences in which they worked out satisfactory arrangements covering such issues as the timing of parental notification and parental input regarding major and lesser care decisions, considerations for scheduling periodic care conferences, and guidelines for communicating and resolving episodic concerns. These parents described it this way:

> They call us about everything. They update us regularly and they're very thorough that way. They call whenever there's a problem. If she has a temperature, or has trouble breathing, "We're doing this," or "We're doing that." Any big thing, we'd be called ahead of time. If she had a fever and they gave her Tylenol, they don't call to ask us.
>
> They know me well enough that they know I want to be contacted. They know I panic if he's really medically having a problem. They usually let me know that he's having problems breathing or whatever and thought they'd like me to know and I usually come up there. But there'll be times that they call me and they'll say, "No, nothing's wrong; we're just calling to tell you this. . . ." That's something which relieves me, which really helps because they know I'm a worry wart. But they're real good about contacting me if he's sick. . . . They call me no matter what time of day. And I like that. And I'll just express my. . . . I will ask questions and ask, "What's being done? and how much is he getting of this or that? and how often?"

"Establishing supportive connections". The code, "Establishing supportive connections," was defined as parents' seeking and acceptance of others' assistance and willingness (or not) for disclosure. During the individual interviews, parents were asked whom they considered a source of support among the facility staff and what their experiences had been with parent support groups. Many parents mentioned various staff members within the facility with whom they felt a particular bond and whom they considered a source of support and information. Most parents identified registered nurses in various positions, such as head nurses, resident care managers, and staff nurses; nursing assistants; and social workers. Some also mentioned other categories of staff. A couple of parents were unsure of the professional identities of staff members whom they knew only by first name.

A few parents acknowledged individuals they perceived as supportive of their child, but did not consider anyone on the facility staff to be a source of support for themselves. A couple of parents stated that they had become accustomed to functioning with little understanding or support from others, and had not asked for any support from facility staff. One parent described,

> Actually, I wouldn't consider anybody here a source of my support. There are a lot of people that are close with my child and they all know me, but as far as me talking with them about him and them being the support, I don't. . . . Nobody asks me how I'm doing . . . well, people here and there, but that's just a matter of being polite.

All parents acknowledged that supportive connections were helpful, but not all parents succeeded in establishing them with facility staff. One parent stated that openness to support came with increased trust in the facility staff over time.

Most parents related that support groups were offered by their facilities, but they had not participated. They felt emotionally and physically exhausted, and not ready at the time their children were first admitted. Even later in the child's stay, they had trouble summoning up the interest and the energy to participate in a group.

More than twice as many mothers as fathers participated in this study. Fathers and mothers who participated in the study observed that fathers seemed to have particular difficulty establishing supportive connections. These parents conjectured possible reasons for fathers' difficulties, including too much pain; too much guilt; too much loss; too much grief; and no way to "fix it." The parents identified ways the facilities helped them to connect, including encouraging the parents to visit any time of the day or night; greeting parents by name or at least as the child's parent; understanding parents' emotional needs; listening, spending time with parents, and encouraging them that they are not alone; frequent communications about the child's condition, care plan meetings, activities, and invitations, which remind parents that they are a part of it all; and facilitating home visits, where parents and siblings can be with the child without feeling that they are in a limelight.

A couple of parents related that they had some experience with parent support groups within their facilities. They viewed them as not particularly satisfactory because of scheduling difficulties with parents' work hours, child care for siblings, poor turnout, poor facilitation, monopoly of the discussion by only one or two people, subject matter they considered irrelevant, and little accomplishment. Parents differentiated between subject matter focused on the inner workings of the facility, such as the numbers, schedules, and turnover of staff, and topics focused on how parents were doing and issues related directly to their children's care. Parents reported being interested in different topics at various times, which contributed to frustration if the chosen topic was not relevant to them at that particular time.

During the interviews, nearly every parent verbalized having felt isolated and expressed interest in meeting other parents. Most parents did not know and therefore could not support each other. They believed it was due to parents visiting at a variety of times, reducing the chances of encountering each other. One parent talked about support in this way:

> I went out with two other parents and we just had dinner and were talking and it was so great to talk to, in that setting, to just talk about what it was like to place them, and just basically the kids' history and stuff. So that was good and I don't think you ever stop needing that, because we are such a small minority. I mean, most families don't know any other family that has a kid in a nursing home, and actually ours is probably the most impaired kid

> we know. . . . It's really hard, feeling so isolated, you only have really each other to talk to about your child, because talking to your family, that just gets them upset. You feel protective of them, and . . . it's very hard.

"Getting my life back". The code, "Getting my life back," was defined as parents' ability to attend to other responsibilities and pleasures of life, due to relief from the daily burden of the child's care. Every parent in the study provided descriptions of ways in which their child's care in the facility changed their lives, such as enabling them to regain their own health, focus on parenting their other children, enjoy time with their spouse, engage in social activities that were previously denied them, and pursue employment opportunities that had been out of reach. As these parents described,

> Just to feel that you get your life back, in a way. It's enabled me to be a good mom to the other kids, which I couldn't do. I couldn't have been there for them, and they would have undergone a lot of stress. Just seems like there was a medical crisis every other week.

> Because now you can just say, "OK, let's go do this now. We're going to go get a Christmas tree." We could never go get a Christmas tree, go get our pumpkin. I mean getting in the car with a wheelchair and all that it took. Getting him ready and being on a schedule of feedings and medications, and putting that around picking up kids, so it was always, constantly in the van,

> picking up kids and dropping off kids, and if they joined a sporting event, thinking, "How am I going to get him there across the sports field?" Our work schedules . . . so I don't know how we did it.

In summary, themes that emerged from the data of parents' experiences with the facility indicated a strong drive for parents to fashion a satisfactory working arrangement with the facility staff regarding their children. There was evidence of a yearning for connections with others who could understand, affirm, guide, and encourage parents empathetically. Several parents described the positive effects in their lives from establishing supportive relationships with facility staff or other parents. All parents in the study described changes in their lives following their child's admission to the facilities which allowed them to focus on other responsibilities and to enjoy life's pleasures.

From parents' experiences, there were data indicating that successful negotiation of their child's complementary care, establishment of supportive connections with others, and getting their lives back led to parental satisfaction with care. Factors affecting parents' satisfaction with their experiences with their children's facilities will be discussed in a later section.

Feedback

One theme, "Vulnerability," related to the feedback element emerged from parents' experiences with the pediatric skilled nursing facilities caring for their children. The feedback element of an open organizational system refers to the action of rendering evaluative information back to its source. For parents in this study, issues around feedback included parents' sense of being valued (or not), their experience of the facility as being open to new ideas, advice to the facility for how it could continue or improve, systems for providing ongoing feedback to the facility, and advice to other parents.

Most parents felt valued and that their opinions were important to the facility staff; they related that their facilities requested their involvement and feedback, appreciated it, and acted upon it positively. They viewed their facilities as open to new ideas whether they came from the staff or themselves. Some parents, however, related that they did not always feel valued. They gave explanations for qualifying their sense of being valued, including: that they felt valued during their children's crises because they could help staff problem-solve based on their past experience, but during routine care they perceived the staff as not wanting their input; or that initially they had not felt valued, but they had taken the initiative to work out a good relationship with the staff and now felt valued; or that their sense of being valued changed with different staff and variations in philosophies; or that the staff seemed responsive to ideas involving the individual child but not necessarily so to ideas involving other parents or the organization's functioning.

All parents described experiences which led them to recommend that the facilities continue or improve certain aspects. With few exceptions, these recommendations involved direct care of the children. Parents' specific recommendations will be discussed in subsequent sections.

"Vulnerability". The code, "Vulnerability," was defined as parents being open to wounding or attack, or at risk for losing something highly desirable. Several parents expressed concerns about providing direct, identifiable feedback to facilities because of fear that their child might be deprived of the facility's care as a result. Most parents in this study were acutely aware of the dearth of resources for their children, and expressed reluctance to interact with their facility in any way that could jeopardize their family's access to it. As these parents stated,

> I know it sounds funny, but I would not want, I wouldn't feel comfortable talking to someone that is directly at [the facility] because in a way, [the facility] is really the only place for her right now, and it's important that she's here. I wouldn't want them mad at me. And I don't think that they would be, but it's just so important that she's here, like it's just the only game in town where she can be, and I just feel lucky that she's still able to be here.

> It's hard to criticize something that's saving your life. You don't want to look a gift horse in the mouth. I tell myself when I go in and her legs aren't covered up and I think her legs are cold, but I say, "OK, I can handle it; no

> complaints." Sometimes it's a little uncomfortable. . . . You don't want to make them mad.

In addition to fears about losing access to nursing home care, parents' experiences evidenced other aspects of their vulnerability. Parents talked about how easily they felt bad regarding their children. For example, they felt bad about their children's conditions and that they could no longer care for them. They felt bad when they felt judged; when they felt devalued; when they felt isolated; when they felt like intruders in the facility; when they had conflicting opinions; and when they feared the staff viewed them as neglectful for not visiting more often.

Overarching Theme

A pervasive theme throughout parents' descriptions and throughout the timelines of their experiences was that of conflicting feelings. This theme was present throughout their pre-admission realizations and decisions as well as during the years their children were in care; and it was part of the dynamic.

"Fiddler on the Roof". "Fiddler on the Roof" was a code that captured parents' experiences of conflicting feelings related to the child's situation. One parent described the phenomenon as similar to the Fiddler on the Roof, who considered an aspect of his life "on the one hand" and another aspect "on the other hand." Parents described experiencing feelings of relief, sadness, guilt, freedom, anger, loss, gratitude, enjoyment of life, and jealousy of staff caring for their child; many of these were felt simultaneously, and these conflicting feelings never completely and permanently ended. Additionally, parents were faced with emotion-laden decisions about their child; neither decision was clearly right "on the one hand" or clearly wrong "on the other hand." As these parents explained,

> I can remember feeling anxious about the fact that I finally realized that I was not just his mommy any more in terms of his actual maternal care. I remember feeling very upset about that and saying to myself and feeling actually jealous of the aides because they were taking care of my son, holding him, loving him for me. Yes, there's a Fiddler on the Roof with everything. . . . On this side, I was grateful; on the other side, I was angry and also jealous because he was *my* boy. They were taking care of my son and I should have been the one. But I knew I couldn't and I felt like he had 15 mothers instead of the one he was supposed to have. That all ties in with guilt. I was feeling very jealous. I thought, "He's *mine.*"

> So there was an increase in freedom which felt a little peculiar. I'll be honest; it was strange. But it also created a sense of profound loss and depression and thinking I wasn't good enough and how could I do this? All the questions and grief and loss issues came up that could come up.

Parents were often emotionally vulnerable to changes. If factors changed in the organization, the balance of positive and negative feelings easily changed as new positive or negative factors came into play.

In summary, 21 themes were identified from parents' experiences with the pediatric skilled nursing facilities caring for their children. These emergent themes were presented in a format corresponding to the elements of an open organizational system, which was the framework used to develop the interview guide.

Parents' Experience with Family-Centered Care

The second part of Question 2 was, "How do parents describe the family-centered care elements they experience in pediatric skilled nursing facilities?" In order to answer this question, parents' descriptions in all individual and group interviews were analyzed and compared to pre-existing codes of the accepted elements of family-centered care.

Family-Centered Care Elements

Most authors writing about family-centered care agree on the following key elements: the family as the constant in the child's life; family and professional collaboration; exchange of complete, unbiased information; respect for the diversity of families; respect for diverse coping methods; encouragement of peer networking and support; incorporation of children and family developmental needs; implementation of appropriate, comprehensive policies and programs that provide emotional and financial support to families; appreciation of families as families; and assurance that the designs of health care delivery systems are flexible, accessible, and responsive to family needs (Ahmann, 1994; Brown, Pearl, & Carrasco, 1991; Shelton, Jeppson, & Johnson, 1992; Shelton & Stepanek, 1995). Parents' experiences with pediatric skilled nursing facilities supported the relevance of the concepts inherent in the 10 accepted family-centered care elements, although the language was rarely the same. Some family-centered care elements were referenced more than others in descriptions of the families' experiences.

Excellent quality care. Excellent quality medical, nursing, and habilitative care was of the utmost importance for the parents in this study, whose children were medically fragile. It was this need that impelled parents to make their agonized decisions to admit their children to the nursing facility. Yet, explicit statements of excellence in quality care based on clinical competence were not found in the accepted key elements of family-centered care.

Parents repeatedly expressed their vigilance about the quality of clinical care. They verbalized expectations of clinical competence and included with it a knowledge of the child, monitoring, recognition and evaluation of symptoms, and prevention of complications, as well as medically and physically safe environments. They also included comprehensive therapies, activities, developmental stimulation, and their children's interactions with varieties of people as components of their concepts of high quality care.

Family as the constant in the child's life. As an example of the variation of language used by families and professionals, parents did not make references to "the family as the constant in their child's life." They did, however, relate acute and ongoing awareness of their children and their efforts to maintain them as part of their families. As one parent explained,

> He's my son. I've never forgotten he's a part of my family. He's my son; I've never forgotten that. You know, even though he's not a part of my daily life like my other son is, you know, I take him to soccer practice and cub scouts and all that, you know I'll never have that kind of relationship with Dale, but I don't forget for one minute that I have another son here.

As an aspect of maintaining the children as part of their families, there were many comments from parents regarding their appreciation of facility-sponsored outings and activities which parents viewed as providing opportunities for keeping parents and siblings involved with the children. Parents expressed wishes for even more such activities, scheduled at a greater variety of days and times, to increase the possibility of working parents' participation.

Parent/professional partnerships. Similarly, parents did not refer to partnerships or collaboration. Virtually all parents, however, described components of parent/professional partnerships such as establishment of trust, information-sharing and communication, respect, understanding, negotiation, competence, decision-making, and fulfillment of expectations.

Emotionally supportive policies and programs. Parents verbalized that welcoming, hospitable behavior by facility staff made considerable differences in their families' lives. Seemingly small gestures such as staff introducing themselves to parents, calling people by their names, and asking whether there were anything they could do for the family had a significant effect. Respecting the family's privacy and the child's personal belongings were conducive to the parents' emotional well-being. Making parents feel welcome, rather than conveying the idea they were intruding or inconveniencing the staff, was important for a sense of hospitality. Asking parents how they were doing, in a more meaningful way than merely politely in passing, profoundly affected parents. Some parents said that such a level of interest was never shown them.

Encouragement of peer networking and support. Many parents described facility efforts to provide parent support groups. The support group sessions that some parents attended were portrayed as characteristically more information-sharing than encouraging of peer support. However, bringing parents together for information-sharing can be a first step toward their getting to know and support each other. Some parents related that, due to confidentiality, there were barriers within the facility to learning other parents' names or phone numbers. At the time of the interviews, these barriers had not been overcome.

Incorporation of children and family developmental needs. Several parents described surprising and often distressing developmental changes in siblings. As they grew older, many siblings became uncomfortable visiting the medically fragile child. Some children were reluctant to initiate physical contact, such as hugging and kissing their brother or sister. Some seemed more awkward around the sick child than previously; a few children became quite upset by visits. Most parents reported that they were unprepared for these changes. A few parents described feeling irritated with their children's new behaviors. One parent related being helped by the facility staff to understand the sibling's developmental needs. Several other parents expressed their need to have anticipatory guidance to understand a variety of developmental changes within their family members.

In summary, parents in this study related experiences that supported the 10 key elements of family-centered care. In addition, they repeatedly identified excellent quality clinical care as their most important concern, although this was not yet found to be explicitly stated as a goal in the literature.

Parents' Perceptions of Facility Strengths and Weaknesses

The third part of Question 2 was, "What do parents identify as the strengths and weaknesses of the facilities caring for their children?" In order to answer this question, parents' descriptions of their experiences in all individual and group interviews were analyzed, focusing on features of the facilities which most parents praised and features they described as needing strengthening. Parents described a plethora of experiences leading them to characterize facility practices as strengths or weaknesses. The primary organizational strengths and weaknesses which most parents mentioned in the interviews will be identified next.

Organizational Strengths

Parents described strengths in the organizations caring for their children. Six areas of strength which parents mentioned frequently will be described: high quality care; caring; keeping the family involved; decision-making; communication; and team spirit.

High quality care. Overall, substantially all parents in this study considered their children's care to be of high quality, and praised the facilities for it. They stated that their children's physical, emotional, and developmental needs were met, and that their children were kept comfortable. Most parents mentioned the children's therapy services and activities as positive elements. Several parents commented on how well their children's care was integrated. However, some parents identified specific aspects of their children's care that troubled them to varying degrees, such as having to convince nursing staff to involve parents in decision-making, and staff failing to follow up on children's symptoms.

Caring. There was no doubt in parents' minds that the staff of these three pediatric skilled nursing facilities truly cared about the children there. Although some parents described experiences they found disquieting or in which their own needs were not met, nevertheless they were convinced of the staff's concern and affection for their children, which compensated for a great deal. One parent stated, "I think they're excellent. I really do. I think they just really care for the kids."

Another parent explained, "If I were advising other parents, I would tell them that people in the facility really do care about the kids."

Keeping the family involved. Most parents expressed appreciation for the facilities' efforts to keep families involved with the child in care. The connections most often mentioned were involving the parents in care decisions and involving the families in facility-sponsored activities, for example, summer picnics, Thanksgiving Dinners, Christmas parties, and outings such as Disney on Ice.

Decision-making. Overall, parents related positive experiences of participation in making decisions about their children's care. Parents participated in regularly scheduled care planning meetings as well as episodic personal and telephone conferences when their children had medical crises. Although not all aspects of each decision were trouble-free, parents portrayed their roles in decision-making as a facility strength.

Communication. Essentially every parent described highly positive experiences with the facilities' efforts to keep them informed. Although some aspects of communication were problematic, overall parents praised the facilities for their commitment to parent communication.

Team spirit. Virtually every parent spoke enthusiastically about the team spirit they observed in the facilities. Parents saw that staff worked really well together and helped each other. They felt the staff had a good fellow feeling for each other; parents observed no bickering, and the staff seemed to want to be working there. One parent said, "I see teamwork. I think they do teamwork very well. There's more teamwork there than where I work." Another parent stated,

> I think they all work very hard, and they all see each other working very hard, and they, it's one of the few places I've ever seen people working, they respect that in each other and do what they can to make it easier. There's nothing better than going into somebody's workplace and hear people laughing. I don't know if that's just me, or is that just a common thing that I, I just love to go and hear people working and enjoying themselves.

In summary, parents viewed the facilities caring for their children as staffed with employees who cared deeply for their children and each other, who worked well and harmoniously together providing clinically competent, comprehensive care meeting the children's physical, emotional, and developmental needs. Parents believed the facility staff communicated well with them and involved them in making decisions about their children's care. They appreciated the facilities' efforts to provide opportunities that helped keep parents and siblings involved with the children in care. These positive features were consonant with parents' ideas of what should be the facility's major tasks.

Organizational Weaknesses

Parents described weaknesses in the organizations caring for their children. Six areas of weakness which parents mentioned frequently will be described: staff turnover; organizational stability; parental understanding of funding mechanisms; parent support; sibling support; and basic hygiene.

Staff turnover. Every parent participating in this study, that is, parents whose children were in all three facilities, related major concerns about direct care staffing. They described multiple instances of experienced staff familiar with their children's conditions and needs leaving for what parents perceived were higher paying positions. They related that favorite staff had left, sometimes even without having the opportunity to tell the parents goodbye. Parents described experiences of agency staff or newly hired but inadequately oriented, inexperienced staff being assigned to care for their children, when parents believed that these staff were unfamiliar with their children and, therefore, unsafe. They feared that inexperienced staff would miss serious signs, such as those indicating impending seizures. They believed that inexperienced staff did not know such things as how to put on their child's specific brace or what was the optimal feeding position. Most parents were understanding of periodic emergencies, such as illnesses affecting large numbers of staff. However, their concerns focused on chronic patterns of staffing with inadequate numbers or levels of competency.

Most parents expressed frustration as well as loss that many of the staff members they knew and trusted with their children's care left for higher-paying jobs. Parents needed to be able to depend on consistent, competent staff. At all three focus group meetings, parents introduced this issue and discussed it at length. The cause of the problem was seen to be inadequate funding of the facilities. Some parents verbalized their concerns this way:

> Consistent, adequate staffing. Maybe it's obvious, but really competent staff. Competent and they love kids. And the staff has a good schedule so that there's not a lot of burn-out. They're not working really long hours or doing double shifts or. . . . And they need good pay and good benefits and good working conditions to attract the best quality staff. . . . The administration [should be] committed to recruiting, training, and keeping good staff. I think the head nurse position is crucial. Maybe when that person retires, that a number of people are involved in a committee that includes families to make sure you get somebody who is good.

> Good pay and good benefits and good working hours so that they can afford to keep their people. I think that's how you keep people. I think there should be an adequate number of people so that people don't have to work long hours. And then the more I thought about it, it really needs to be a non-profit organization because if profits are at all involved they are going to sacrifice to meet the budget so it has to be non-profit. I know they have to make their ends meet. And this kind of goes without saying because I don't know why you would be in this business if you didn't, but the organization needs to be dedicated to quality of life.

> I don't understand why with the good work they do, there isn't more publicity and more fund-raising. It was one of the conversations that I had with another parent, "I wonder how much money it would take to raise everybody's salary here a couple of bucks an hour."

Parents expressed the strong belief that the staff turnover issue negatively affected their children's care. Parents' comments indicated that this issue also strongly affected their own trust, peace of mind, and satisfaction with care.

Organizational stability. Most parents expressed anxiety about the long-term stability of their child's facility. Their concerns were verbalized as insecurities about the facilities' commitment to pediatric skilled nursing care, particularly in the mixed facilities; worries about the facilities securing sufficient funding to operate; anxieties that funding problems might cause the facility to close; misgivings about the relatively small number of pediatric nursing home beds in the state and that some families would have to go without services; dread at the thought of being without the facilities themselves; uneasiness about rumors that their facility wanted to admit younger children; apprehensions about available appropriate care for their children as they grew older; and chagrin that their own questioning or challenging behavior might jeopardize their child's care or lead the facility to terminate its pediatric program. One parent explained, "[I want] financial stability. . . . I want organizational stability. I don't want a lot of turnover at the top, people leaving and coming and not just staff, but people who set the course for where the organization is going." Other parents stated,

> In Oregon, there still aren't any more resources out there. Where else could we go? That's a hard one because I know a lot of parents fall into that, "Well, this is all we've got, so we can't ever criticize. We've just got to put up with whatever happens."

> Yes, I worry about where do they get their money? What if their money doesn't come? What if someone's giving them money every year, and that person goes away? What would happen when our child gets older, and she's not there?

Parental understanding of funding mechanisms. Most parents related that their child's facility had not explained how it was funded and what kinds of fund-raising needs it had. Parents expressed varying degrees of anxiety about the facilities' viability, but there was little understanding of the funding mechanisms. Parents worried about their facility's level of funding in particular with regard to staff turnover and facility stability. A few parents expressed willingness to assist with fund-raising activities, or related that they had done so in the past. Some advised that their facilities should strengthen their public awareness and fund-raising programs in order to achieve greater financial stability, yet even these parents had only vague understandings of the facilities' funding mechanisms. One parent explained, "I don't know about the funding. . . . There's never a plea made, and they never let us know that they are short of anything." Another parent commented,

> I worry about some things, the funding and stuff. When they have things . . . we always try to attend . . . to raise money for them, which I think is a great idea. They should do more to keep that going. I think they have enough . . . maybe they don't. I don't know.

Parent support. As reported in a previous section, many parents verbalized feelings of isolation; they had few connections with family, friends, or facility staff whom they believed understood their situations and did not negatively judge them. Even parents who felt connections with various staff members lacked access to other parents, due to factors such as confidentiality, which limited distribution of names and phone numbers, and extended visiting times, which reduced the chances of visitors encountering each other. Parents in this study regarded support group efforts within the facilities as nonexistent, irrelevant or they weren't ready for them. One parent described,

> It took me about 2 years after my child was in the facility to figure out what I was feeling. . . . I'm not sure if this makes much sense or not, but everybody grieves at a different level and different time. I did not want that need to be met for me at that point. I wanted to be alone with my pain for awhile. I didn't want to share that with other people.

An effect was that many parents were pleased with the supportive care their children received, but were without support themselves. One parent commented,

> I'd like to see some kind of matching of new parents with veteran parents when you go so that you can have someone to ask questions, you can call. Some kind of an initiation booklet, too, with numbers and names of staff, especially when you first go in. Some kind of nice little compilation of what the routines are, visiting hours, "We can help with this," and "This is your staff," even though they do change. I can't even tell you how long I've been there and I don't know all the staff names just because after the first year, you don't want to say. You know them by face but I'm bad at names and I don't want to look at their name tags after all this time. . . . I want to be able to know the people who are living with my child. . . . So I'd like some kind of newsletter with profiles of the kids and staff. Something that makes you feel like you have a community because we feel so cut off from the rest of the world.

Sibling support. Most parents in this study had other children at home. All these parents discussed concerns they had about them. Some parents verbalized their worries about the effect their distraction with the medically fragile child had on siblings. Some parents reported that their younger children voiced anxieties that if they got sick, their parents might place them in a facility, also. Most parents fretted about their children's relationships with the medically fragile child as the siblings got to their pre-teen and teenage years; they became uncomfortable and embarrassed around the child in care. Parents described that after saying hello at a visit, the siblings had little to do, other than perhaps watch a video. While the parents hovered around the medically fragile child, the siblings were distant, restless and bored, although parents wished the children shared their interest.

Nearly all parents expressed the need for assistance with sibling issues and had not found it. Several parents pointed out ways in which the facilities could help families understand their children's developmental changes and adapt to new circumstances. Many parents suggested that facilities could assist them with anticipatory guidance. Most parents found that special activities oriented to include families provided a focus that siblings could enjoy. A couple of parents believed that for siblings, special events were opportunities to be reminded that their sibling was different. A few parents suggested that something like a Brothers' and Sisters' Night, with parents in the background, might be helpful for nurturing siblings' relationships with the medically fragile child. Some parents suggested counseling sessions or support groups for siblings only, to help them adapt to their own developmental changes, and to learn new ways of relating with their medically fragile sister or brother. One parent said,

> We're all a family unit: the kids here, the other siblings, and us. She and I have gone through what we've gone through, while the kids have, too. There

> has to be a tremendous interplay going on with those little guys, too, with all the siblings. I don't know what they may need.

Basic hygiene. Many parents initiated discussions about the children's basic personal hygiene during all three of the focus group interviews as well as during some individual interviews. Parents were concerned that their children looked clean and presentable. All the children discussed were incontinent and unable to engage in any grooming or self care. Many children were teenagers, with increased skin and scalp oiliness. Parents talked about children needing to be bathed daily. They wanted to have the children submerged in warm water, rather than hosed off in a shallow tub. Parents requested more frequent shampoos, and regular cleaning of their children's ears, eyes, mouths, and faces. A couple of parents voiced distress at coming to visit and finding their children with dirty faces from dried crustiness or bits of crushed medications. The parents attributed problems with hygiene to lack of sufficient numbers of staff members to do basic care.

In summary, parents were deeply concerned about turnover of facility staff and the negative effect they believed it had on their children's care, including basic personal hygiene. In general, parents were anxious about the organizational stability of the pediatric skilled nursing facilities caring for their children and worried about resources for their children as they became young adults. However, they acknowledged that they did not understand the funding mechanisms or fund-raising needs of the facilities; lacking facts, their anxieties were vague. Parents appreciated the supportive care their medically fragile children received; however, efforts within the facilities to provide organized support to parents and siblings were weak.

Parents' Satisfaction with Pediatric Skilled Nursing Facilities

Question 3 was, "What factors affect parents' satisfaction with their experiences with pediatric skilled nursing facilities?" In order to answer this question, the researcher analyzed parents' responses throughout the individual and group interviews, with particular focus on two sets of questions in order to identify factors affecting parents' satisfaction with care. Question 13 of the individual interview guide was, "What has been your experience of parent satisfaction, including your own?" The final questions in the focus group discussions were, "What has been your experience of satisfaction in your child's pediatric skilled nursing facility? Have you experienced a change in your overall comfort or satisfaction over time? Was it in 'comfort' or 'satisfaction'? Is there a difference? Which direction was the change as time went on, more or less?"

Descriptions: Satisfaction and Comfort

Satisfaction can be considered as adequacy or sufficiency. Comfort can be considered as security: release from doubt or tension. The parents participating in the focus group discussions described *satisfaction* as an adequate job; they identified *comfort* as being "a step or two above the base line," at which they could relax their vigilance and worry. They equated comfort with trust, which often developed over time as they watched the staff function and came to know and like them.

Parents described their satisfaction and comfort in various ways. The descriptions of the levels of satisfaction with their children's care ranged from "pretty satisfied" to "close to perfect." A few parents stated that they were satisfied from the very beginning of their child's stay. Some said that they were satisfied from the beginning, but that their comfort increased as time went on. Some said that they had become more comfortable over time but that there were occasional areas of dissatisfaction. A couple of parents said that they became more comfortable because they knew the facility and because they were more used to the idea of the child's not being at home. Some said that their comfort levels depended on stability within the facility, and the knowledge and skill of their child's direct care staff. Three parents explained,

> Satisfaction is a certain basic level and comfort is a few degrees up. Every once in awhile the apple cart gets disrupted. Say if there is a staff shortage or they bring on a bunch of agency nursing and the comfort level goes down. My satisfaction is okay. We get through this and it goes back up but it still sticks in your head as to why this happens. It goes from satisfaction with care versus satisfaction with the administration being able to supply the care.

> When you are admitting your child, usually it's because of circumstances. You've got to make it work so you've got to *make* yourself be satisfied. I won't say that I was ever satisfied that first week or two, just the relief of

> having something done for her. You hope and pray that those people are going to take care of your child, even though you've had all these other people telling that it's a great place and they take good care of them. You have to visually see and hear that for yourself before you get that satisfaction and then once you get that, then your comfort level starts.

> Over the years I have come to trust the staff at the facility. That's what they are there for. So I trust their level of expertise. I've watched them. And I trust them and I know the staff and I like the staff--as long as they don't leave. That really upsets my equilibrium. My comfort level goes down, too.

Factors Associated with Satisfaction

Parents' discussions of satisfaction and levels of comfort linked three major themes with satisfaction. These themes, which emerged from the data of parents' interviews, were Negotiating Complementary Care, Establishing Supportive Connections, and Getting My Life Back. In addition, data from the interviews suggest that finding meaning through faith or engaging in activities advocating for their child contributed to parents' sense of satisfaction.

Negotiating Complementary Care

Parents frequently referred to the growth of trust and the time it took, even though some parents arrived at a comfortable level of trust sooner than others. Trust was shown by parents' data to be a prerequisite to forging an interdependent arrangement of complementary care, wherein both parents and facility respect, honor, appreciate, and utilize the contributions each makes to the holistic care of the child.

Establishing Supportive Connections

Some parents referred to getting to know and liking the facility staff, a prerequisite for establishing supportive connections within the facility. Knowing and liking the staff did not result in supportive connections without initiation and follow-through on the parts of both parties, however. Supportive connections were sometimes established with empathetic others outside the facility.

Getting My Life Back

There were data from the parents' descriptions that indicated that successful negotiation of complementary care and establishment of supportive connections allowed parents to "get their lives back." In other words, parents who were secure about the care their child was receiving and their degree of participation in it, and whose needs for support were met, were freed to attend to other responsibilities and pleasures of life. Negotiating complementary care, establishing supportive connections, and getting their lives back generated parent satisfaction.

Advocacy and Negotiation

A few parents commented that they had been the only ones who knew all about their children, and that they became more comfortable as they learned to speak up, to advocate for their children, and to negotiate for them. These parents' comfort levels were linked to their ability to negotiate and advocate for their children.

Age at Admission

In one focus group discussion, two couples had children who were admitted very young (under 2 years of age), some parents had children who were admitted when they were considerably older (pre-teen and teenaged), and a couple had children who were admitted at ages between these. The parents compared and contrasted their experiences and questioned whether their levels of satisfaction, relief and wrenching might be linked to the age of their children at admission and the length of time they were cared for at home. One parent concluded,

> I guess it depends on what place you're at, at the time. That's a big factor. I don't know what I would have been like if I had to give up my child at 9 months instead of 2½ years. And to go from a foster home . . . I had some stepping stones and that was why I was at the point I was of being very satisfied, having talked to the nurses. And I was told by my child's neurologist about this place. And it was closer to us. . . . I think a lot of it is where you are at in your child's life.

Faith and Meaning

More than half of the families in this study (*n* = 9) made explicit references to the role their faith had in finding meaning and degrees of satisfaction and comfort with their children's care. These parents described an equanimity arrived at through faith that gave them greater understanding and strength; their faith did not, however, spare them the pain of their children's conditions. These parents commented,

> I don't know about research, but God certainly got us through this. I would have to say that was my biggest factor. His helping me to get to the realization part of things. We have come to a kind of a peace over the years, you know. Our child is kind of out of our hands, really. I mean, you know, we just kind of offered him up to the good Lord, I mean, you know, whatever will be, will be with him. And you know, we kind of accept that.

> Faith wasn't important to me until our child was born and started having trouble. Now it just seems like God is there all the time. I don't even have to think about it. I know someone is keeping a special eye on him and he has angels around him. . . . You know you have to work out that relationship with God. You have to be able to have some peace about the situation. . . . We were given the strength to turn it into a winning situation. . . . It made us see what's important in life. . . . It's a difficult path but it was real rewarding.

In summary, factors that affected parents' satisfaction with their experiences with pediatric skilled nursing facilities included time for parents to develop trust in the facility staff and their competencies; ability to negotiate complementary care, establish supportive connections, and get their lives back; and value-added qualities beyond the basic care parents expected the facility to provide. For some parents, satisfaction was affected by their ability to become advocates for their children. For some, finding meaning through their faith facilitated their satisfaction and comfort. A few parents introduced the question of children's ages at the time of admission to the facility and the length of time they were cared for at home as possible factors affecting parents' satisfaction.

Parents' Descriptions of Their Ideal Pediatric Skilled Nursing Organization

Question 4 was, "What features do parents include in an ideal pediatric skilled nursing organization?" In order to answer this question, data from the three focus group sessions and the individual interviews were analyzed. Although some of the data that were analyzed came from individual interviews, most came from parents' contributions during the focus group interviews on three facets of an ideal pediatric skilled nursing facility: features related to the facility's environment; features related to the facility's program of care; and features related to the organization providing care. The following features are the results of parents' dreams of their ideal pediatric skilled nursing facility.

Features Related to the Facility's Environment

Parents described the environment of their ideal pediatric skilled nursing facility as cheerful, warm, and child- and family-friendly inside and out. The facility is located in a residential neighborhood with plentiful grass and trees, rather than on busy city streets. There are outdoor gardens and quiet park-like areas with flowers and trees, easily handicapped accessible, where parents can push their children's wheelchairs along winding paths. There is a large outdoor playground area with swings and other equipment for children in wheelchairs, with volunteers available to help operate the equipment.

The modern, up-to-date building is welcoming and inviting to parents and visitors, with unlimited visiting hours, ample parking and an easily accessible entry, but with reliable security. Preferably, the building is small, limited to one or two stories. There is a home-like environment, rather than a sterile, medical, institutional feel. There is a sense that children live there; that it is their home.

Inside, the building is a spacious, open, colorful, inviting environment, with plenty of natural lighting through skylights and large windows looking out to nature. Carpeting, pictures, couches, indoor plants, music through a sound system, and a play area add to the home-like feel. The facility is clean and sanitary, with plenty of fresh air and a pleasant smell. The building has functional heating and cooling systems for comfort. Although the facility is bright and tastefully decorated, the atmosphere is quiet, calm, and peaceful.

Children may be grouped in family-like clusters of 4 to 8, with each unit having its own consistent registered nurse, certified nursing assistants, and at least one other staff person. Children are assigned to double rooms in age-appropriate groupings, so that they have one roommate but not more. The children's rooms have space personalized with decorations and family photos according to the parents' wishes. The arrangement provides privacy for each child. The floor plan may group the bedrooms around a central nurses' station, common room, and private family room.

Large, deep bathing tubs allow frequent immersion baths rather than shower baths. There is a hair salon for shampoos and hair cuts.

Each bedroom has a handwashing sink; spacious built-in closets, drawers, and shelves for children's personal belongings; ample bulletin board space for displaying personal cards and photos; and room for a personal TV and radio. There is a recliner or lounge chair for parents' overnight stays during a critical illness.

There is a large school room for education, developmental stimulation, and therapies. There is also a large play room for fun, entertaining activities.

There are comfortable visiting areas designated for family use only, which do not double as overflow storage. There are small get-away visiting areas for parents who wish privacy, as well as large areas for an extended family to celebrate a child's birthday or where families can visit together with other families. There are also visiting areas where parents and siblings can enjoy activities as a family with the child in care, for example, snuggling and watching a video together. The visiting areas are family-oriented, with the expectation that siblings may be active and noisy. There is a sibling area, with activities for a variety of ages. The visiting areas are equipped with a communication system to alert nursing staff to both emergency situations and routine needs, such as assistance lifting a child.

Features Related to the Facility's Program

Parents described the program of care provided in their ideal pediatric skilled nursing facility as of excellent quality, child- and family-oriented, comprehensive and holistic. Care is loving, provided by well-trained, competent, committed, and consistent staff knowledgeable and experienced with medically fragile children, who view their care as a mission rather than as a task. The care providers want to be there, rather than dreading going to work. They do what is best for the child rather than what is easiest for themselves.

There are ample staff to provide a high degree of one-on-one, hands-on care for each child. The child's comfort is of utmost concern. A program is designed specifically for each child which includes: top quality medical and nursing care; individually prescribed in-house therapies for all children, including position changes and hydrotherapy; good hygiene with frequent immersion baths and shampoos of comfortable water temperature and attention to ears, eyes, and mouth care; in-house dental care; good nutrition with healthy, fresh food in variety; year-round education programs appropriate to the child's needs; developmental stimulation; year-round schedule of activities including regular outdoor activities five times a week; and social interaction with other children, staff, and outside community groups. Children's activities are scheduled to encourage the participation of working parents. A family-oriented interdenominational religious service is held monthly. Volunteers, including Foster Grandparents, who enjoy just holding a child's hand, are available daily. Children are safeguarded from physical, emotional, or sexual abuse.

Monthly visits of the child's pediatrician are scheduled to allow parents access and to encourage their participation. Consultants and specialists not only are available to children and parents but also actively initiate assistance.

Children's and families' personal belongings are respected and kept separate from others'. Each child has an adequate share of equipment and supplies to use. There are excellent laundry facilities so that children's clothes look and smell good.

Staff in the facility focus on all aspects of each child's changing personal needs, paying attention to details. Children's basic skill levels, preferences, and idiosyncracies are identified and posted at the bedside.

There is a designated patient care manager. Care is structured so that staff tasks are assigned and communicated at the beginning of the shift. Employees at all levels are well trained.

Staff and parents recognize and know each other. Staff are open to new ideas. They inform and involve the parents, respect their wishes, and incorporate them so long as the request is not detrimental to the child's care. Decisions are made using a team approach, with each team member's ideas considered crucial. Parents are members of the team, along with nurses, nursing assistants, physicians, specialists, therapists, and administrative staff. The team sets goals with parents' input, and works toward achieving them. Advance directives are in place for each child.

There are systems of ongoing, accurate, constructive, and respectful communication among families, staff, and administration regarding the individual child's care as well as facility issues in general. Some parents wish to be notified of changes in their child's status in the middle of the night and others prefer to wait until morning; 24-hour communication is individualized to parents' preferences for issues and timing.

Regular care plan meetings are scheduled to include parents and staff. For parents who live at a distance, video conferencing and e-mail are used to allow parents to participate in their child's care planning. A journal is kept at the child's bedside with daily entries by parents and staff for communication with each other about minor but important aspects of the child's day, particularly if nurses are busy when parents visit. Accurate medical and nursing records are accessible to the parents. Photos of the child's activities in the facility are sent home monthly to parents who are unable to visit frequently.

The facility assists parents and siblings with transitions including admission, room assignments, and changes in medical status. Family privacy is respected; at the same time, parents are notified before entering the room when their child's roommate dies or is hospitalized. The facility provides family education regarding orientation to the facility, understanding the child's condition, and anticipatory guidance about expected developmental milestones, including sexual development. There is an orientation booklet for families of newly admitted children. A parent-to-parent network pairing veteran parents with those of newly admitted children is encouraged and facilitated. There are ongoing monthly support groups for parents and for siblings. There are ongoing appropriate activities in the facility for siblings of all ages.

The facility appreciates that families feel whole when all members are together at home; it encourages and assists families with planning and organizing home visits. A facility van with a wheelchair lift is available to facilitate getting the child home. Lifting assistance is facilitated where needed.

The ideal facility provides a continuum of needed services. It offers in-home nursing services to families not ready to place their child in long-term care. Respite care for children still at home is provided and well publicized, with notices posted in a variety of professional and public places. The facility collaborates with other agencies or itself provides skilled nursing care for medically fragile young adults who have reached their legal majority.

Features Related to the Organization Providing Care

Parents described the organization sponsoring their ideal pediatric skilled nursing facility as dedicated to quality of life for all; committed to a sincere, authentic, heartfelt goal of quality care; having a humanitarian mission; sensitive, respectful, and welcoming to parents with an open exchange of information and ideas; organizationally stable and financially solid; and concerned more about the needs of the children than profit. Many parents preferred that the organization be nonprofit; a couple of parents stated a preference that the organization espouse Christian values.

Without exception, parents wanted the organization to be committed to recruiting, training, appreciating, adequately compensating, and retaining good quality staff in adequate numbers to provide optimum care. Parents believed that staff salaries, benefits, and incentives should be increased and their hours and working conditions improved in order to reduce turnover, including that of administrative and supervisory staff. Compensation should be comparable to that of acute care facilities. Work schedules and the length and numbers of shifts should be designed to safeguard against burnout. Ideally, the job is enjoyable rather than a task. Parents viewed consistent staffing as crucial for providing caregivers who are experienced in the care of medically fragile children and knowledgeable about the individual child's idiosyncracies. As well, consistent staffing is essential for maintaining parents' trust, satisfaction, and comfort with the level of care provided. Parents wanted to be included in interviews for the critical position of head nurse.

In the ideal facility, all levels of staff, including administrative, supervisory, professional, and direct care, are well-educated, trained, oriented, and mentored. They are people who want what is best for the child; they provide more than merely maintenance care. The organization delegates responsibility, encourages independent thinking, measures performance, and rewards above-average work meaningfully. The ratio of direct care staff to supervisors and administrators reflects the organization's commitment to quality care. Administrative staff assist with direct care should there be a staffing shortage.

The organization uses a team approach, and welcomes parents' input and involvement regarding children's direct care and facility operations. Parents' orientation to the facility includes an explanation of organizational roles and responsibilities. Parents receive an in-house newsletter regularly with staff names and changes. Administration is accessible to parents with a friendly, non-adversarial approach. There are opportunities for families to meet key staff face-to-face. Parents have access to professional staff, such as the pediatrician, neurologist, dentist, physical therapist, and occupational therapist in a timely manner. Social events are organized that demonstrate appreciation for the staff and which parents and children can enjoy with them, such as parties, barbecues, and potlucks.

There is a satisfactory flow of information to parents regarding their child's daily activities and developmental milestones. Parents have input into their child's daily activities. Staff are sensitive to family needs; parents are approached in a non-judgmental manner.

There is open, clear, and timely communication among administration, staff, and parents. The facility develops and implements clear procedures for problem-solving and conflict resolution. There are well-defined and written staff policies.

Staff maintain good personal hygiene, and do not jeopardize the children's respiratory status by the use of perfumes or strong scents. The facility has a no smoking policy; if smoking is allowed in specific areas, there is a superior filter system.

The facility has an organizational structure adequate to assure that systems of safety, security, and checks and balances are in place to protect children, families, staff, and material resources. The organization budgets to assure adequate and appropriate supplies.

At least one full-time social worker interacts with parents and children on an ongoing basis. The social worker facilitates a support group monthly for parents whose children are in the facility as well as for those whose children are still at home. Parents are encouraged to support each other. There is a parent directory to expedite communication among families; parents of newly admitted children are invited to be listed. There is a parent communications board in the facility where families who wish can exchange their names and phone numbers.

The organization pursues a high profile of community awareness and public relations to assist with fund-raising and financial support. The facility networks with other organizations and facilities on local, national, and international levels. It encourages parents to contribute their time and effort to special projects.

Ideally, the facility accommodates individuals for their lifetimes without their having to move to a different setting. Individuals are able to transition from program to program according to age and need.

In summary, 18 parents participated in one of three focus group interviews of approximately 3 hours each. They contributed the features most important to them if they were designing the ideal pediatric skilled nursing facility for their child. The features were grouped by the facility's environment, its program, and the organization sponsoring it.

In the following chapter, the researcher will discuss the results of this study. The implications for pediatric skilled nursing facilities and for future research will also be explored.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

This study was undertaken to address a gap in formal knowledge about parents' experiences with the pediatric skilled nursing facilities caring for their medically fragile, severely neurodevelopmentally impaired children. Eliciting parents' descriptions of their experience provided data on what they identified as strengths and weaknesses of the facilities, what factors influenced their satisfaction with care, and what they viewed as an ideal pediatric skilled nursing organization. This was the first study in a research program whose goal is to develop family-based measures of organizational effectiveness to evaluate organizational performance.

Parents' Overall Experience

As the parents who participated in this study described their experiences, common patterns of their lives with their medically fragile children emerged. Parents in this study, all of whom cared for their children at home prior to admission to a pediatric skilled nursing facility, experienced ongoing conflicting feelings; depletion of their own resources to care for their child; a search for competent and loving caregivers; giving over their child's care to others; perpetual guilt, worry, and vigilance; adjusting to new parental roles; developing trust; feelings of being isolated, judged, and vulnerable; pursuing a care-decision partnership with the facility; yearning for supportive connections; and regaining the ability to focus on other responsibilities and pleasures in life as well as those associated with overseeing the care of their medically fragile child.

Enduring Themes

Some themes were tied primarily to parents' initial experience, such as the preliminary letting go and turning over the child's physical care, although it could be said that some aspects of these were repeated each time parents reevaluated their decisions. Other themes recurred throughout the child's stay. Some of the most salient ones follow.

"Need to Know My Child is Cared For and About"

The parents in this study described that their most important qualifications for care, as they considered to whom they could entrust their children, were 1) high quality nursing and medical care, therapies and activities; and 2) loving. Parents expected high quality clinical care. However, they also earnestly wanted their children to be loved by the people caring for them. They hoped for it; at the same time, parents realized they could not demand it. When they believed that staff loved their child, it was an added value which contributed to parents' satisfaction and comfort with their child's care. Providing good quality care which is loving is something that the staffs in these three facilities do very well.

"Guilt and Worry Are Constant Companions"

Parents described absorbing guilt from so many sources, including themselves, that they seldom seemed to be able to be free from it. Most parents considered their need to place their child for nursing home care to be a personal failure; they "should" have been able to work out a way of continuing to provide the care, no matter what the cost to themselves or the rest of the family. Often this guilt was amplified through friends', families', and even strangers' comments and expectations. Parents worried continuously about whether they were doing all they could for their child and whether the facility was providing optimal care. Parents' guilt and worry could be in the forefront of their minds at times; at other times, it was like background music, but always there.

"Parenting My Child Means Perpetual Vigilance"

Parents were never-endingly vigilant. They could never totally relax their watchfulness when the child was at home or later in the facility, even when parents had trust and confidence in the facility staff. They knew their children well from their time of caring for them, and could read their nonverbal language. They were ever watchful of the staff's knowledge and care of their children. They did not necessarily expect perfection; several mothers stated that their own care was not perfect. They were tolerant and understanding of occasional slips. However, they were greatly distressed by problems that were chronic, and most especially, by frequent staff turnover.

"Vulnerability"

Several parents admitted having fears about questioning practices or criticizing the facility in any way. They were concerned that their direct, identifiable assessment of facility practices might deprive their child of the facility's care. Parents did not want people in the facility "to get mad at them." Parents knew there were few, if any, other options for their child's care and were loathe to jeopardize what they had, even when there were suggestions to improve the care. These parental concerns raise doubts about the validity of questionnaires the facilities might send to parents for feedback, particularly if there was any way in which the responses could be identified.

"Isolation" and the Need for "Supportive Connections"

Parents described their sense of isolation in a variety of ways. There were few people they knew who understood their situations and decisions, and with whom they felt they could discuss their medically fragile child. To friends and family, their child was often invisible. Parents often felt people judged them negatively for admitting their child for long-term care. Aware of their own isolation, parents appreciated welcoming, hospitable gestures from facility staff for themselves, the siblings, and extended family members. Calling parents and siblings by name, introducing themselves to parents, considering how their greeting might be interpreted, making families feel welcomed, showing authentic interest in how family members were doing were staff behaviors that families identified as helpful.

Developing Trust

One element of parents' ability to negotiate complementary care of their child between the facility staff and themselves was their sense of trust in the competence and reliability of the staff. Negotiating complementary care was, in turn, a factor in parents' satisfaction with care. Parents described getting to know the facility staff, experiencing how the staff listened to them, observing the way they went about their work caring for the children, and making judgments based on what they saw. Most parents related that learning to trust the facility staff to take good care of their children took a period of time.

Several references in the literature relating to families and health care systems suggested that over time parents and others tended to become less satisfied with the care their family members received (Calnan, 1988; Donabedian, 1988; Maas et al.,1991; Vuori, 1994). In the focus group discussions, most of the parents in this study stated that they became more satisfied with care as time went on, as they developed greater trust in the facility staff. In addition, parents said that their expectations became more realistic as they observed the facility staff caring for several medically fragile children, rather than only one. In general, satisfaction and comfort levels increased over time.

The parents in this study were grouped according to the length of time their children had been in the facilities. The researcher's artificially imposed time periods did not affect parents' levels of satisfaction; there were no differences found in patterns of satisfaction between groupings. Although time was needed for parents to become satisfied and comfortable with their children's care, the amount required varied individually within all three length-of-stay categories.

"Fiddler on the Roof" (Conflicting Feelings)

Throughout their experience with their medically fragile child and with the facility, parents reported feeling variable and often conflicting emotions simultaneously: on the one hand, sentiments such as relief, freedom, gratitude, and enjoyment of life; on the other hand, guilt, grief, sadness, anger, failure, loss, and jealousy toward the staff caring for their child. Parents experienced tension when the realities of what they were experiencing were different from what others seemed to expect, for example, being told they must be feeling relief, when in actuality, the parent was overwhelmed with grief. The particular combination of conflicting feelings varied with stages in the families' adjustments to the changes in their lives.

Ideal Pediatric Skilled Nursing Facilities

In order to obtain the data on ideal pediatric skilled nursing facilities, parents were invited to dream about the ways they would design an organization for their own child. Most of the data about the ideal facility were gathered during the focus group interviews. Individual interviews were also the sources of some of the data when parents expressed design preferences for environment, program, or sponsoring organizations at that time.

There was a high degree of congruence between the individual interviews, the focus group interviews, and parents' descriptions of their ideal facility. Parents who participated in the focus group interviews often introduced features designed to address problems they revealed during the individual interviews. For example, nearly all parents discussed staffing turnover and other staffing problems during both sets of interviews. Parents who expressed concerns about basic hygiene and frequency of shampoos during the individual interviews contributed ideas for bathing tubs and beauty salons during the focus group interviews; parents who discussed troubles with visiting during the individual interviews later introduced the topic of visiting spaces. The consistency between individual interview and focus group topics was even more evidenced when parents were invited to indicate the features most important to them with an adhesive dot on the newsprint sheet. Rather than objectively ranking topics for an ideal facility, many parents selected features designed to address what they perceived as current program flaws. The length of the focus group sessions precluded reaching consensus on objective features of a hypothetical facility.

The limitations of the focus group sessions also precluded reaching a consensus on some recommendations that may seem conflicting. For example, some parents wanted a small, homey facility of not more than two stories; others listed a maximum of two children per room and multiple types of visiting spaces, all of which add square footage to a building.

Recommendations derived from the parents' perspectives illustrate the values that parents in this study considered important. They do not reflect the perspectives of staff within the facility, and therefore do not include facility design features of concern to nurses, therapists, special educators, administrators, food service staff, and housekeepers, for example. Although the design is incomplete as a blueprint and some "ideal" features may not be practical in a specific facility, parents' concerns can be considered and addressed when facilities are designed.

Organizational Effectiveness: Conceptualization and Measurement

The vantage point from which an individual observes an organization influences that person's belief about its effectiveness and the indicators used to evaluate it. One group of persons with a stake in the organization's performance may well use different criteria for judging effectiveness from those of other groups of constituents. For this study, organizational effectiveness was defined as parent satisfaction with care in the pediatric skilled nursing facilities where their children resided. This definition necessitated that indicators for effectiveness be based on factors that influence parents' satisfaction with care. This study suggests possible indicators of effectiveness that can be used to evaluate pediatric skilled nursing facilities from the parents' perspectives. The most salient indicators of effectiveness can be grouped into two output categories: (a) a system level product (organizational maintenance or stability) and (b) family and child services (family-centered care and high quality physical care. Organizational stability included the organizational resources (inputs) of consistent, competent staffing; adequate financial resources; and organizational changes in response to regulatory requirements. Health care services indicators (transformations) included both family-centered aspects of care and the quality of physical, social, and emotional aspects of care.

Organizational Stability

Parents looked for indications of the organization's long-term commitment to providing skilled nursing care to children, and wanted stability in administrators and managers, who are the organization's policy makers. For most parents, locating an appropriate facility and securing their child's admission was a lengthy and emotional process. Worries about organizational commitment to children, adequate funding, and apprehensions about care availability for older children contributed to families' insecurities and turmoil.

Consistent, Competent Staffing

Parents were deeply affected by who was caring for their child. Frequent staff turnover was devastating to parents and was by far the most important issue raised by parents in this study, mentioned by virtually every one. Staffing patterns which appeared to parents as chaotic or haphazard evoked feelings of anxiety and dissatisfaction with care.

Parents' knowledge of their child's pediatric skilled nursing facility was based primarily on their relationships with direct care staff. Parents assessed whether their goals of high quality and loving care for their children were met through observing licensed nurses, nursing assistants, therapy staff, and others providing direct care to their child. Parents learned to trust the facility or not based on their perceptions of the direct care staff's regard for the child, their attitudes toward care, their clinical competency, and their attitudes toward parents, siblings, and extended family members. Care by sufficient numbers of clinically competent staff who were familiar with the child's habits, preferences, and other idiosyncracies achieved the parents' goals that their child receive high quality nursing, medical, and habilitative care. Staff who loved their child was a value-added satisfaction factor for parents.

When familiar, competent staff left for what parents perceived were higher-paying positions elsewhere, they often were replaced by short-term agency staff or newly hired facility staff whom parents judged as being inadequately oriented and unfamiliar with their child. Parents became apprehensive about their child's quality of care.

Parents' satisfaction increased or decreased in a direct relationship to the quality of care they believed their child was receiving at a given time. The parents who participated in this study recommended that the facilities make renewed commitments to recruiting, hiring, orienting, and retaining adequate numbers of quality staff.

Although parents looked for indicators of organizational stability, they related that they had rare interactions with administrators or managerial staff, whom parents viewed as a significant group of policy makers within the facilities. Due to work schedules and visiting times, parents seldom saw people at this level of the organization, and questioned whether they understood or appreciated family needs.

Changes in Response to Regulatory Requirements

In order for the pediatric organization to achieve stability, it must comply with myriad state and federal regulations. Like other long-term care facilities nationally, pediatric skilled nursing facilities are a highly regulated environment. Facility administrators and managers spend significant portions of their time developing strategies for compliance with rules and dealing with regulatory agencies. These efforts are necessary to assure the facility's survival. In addition to the regulatory group of constituents, administrators interface with many other groups supporting various aspects of the organization, for example, governing boards, advisory boards, fund-raisers, legislators, community agencies, physicians and hospitals, and vendors of equipment and supplies. This study showed that while many parents had anxieties about their facility's long-term viability, most parents were unaware of facets of the organization beyond their own child's immediate care needs, which were, appropriately, their greatest concern. For the most part, parents had no knowledge of state or federal regulations or the facility's struggles to comply with them; the facility's funding mechanisms for reimbursement, operations, equipment or fund-raising needs; or the administrator's role in enabling others and facilitating the smooth functioning of the organization in order to make patient care possible. Most parents did not engage in the organization as a whole, due to their own life circumstances as well as to insufficient explanation from the facility. Opportunities were lost for parents and administrators to understand each others' roles and concerns, and to view themselves as united in a common mission for the children's care.

Adequate Financial Resources

Parents looked for indications of financial stability. Most parents acknowledged that they lacked understanding of the facility's funding mechanisms and fund raising needs. The facility had not explained the processes to them; without having specific information, nonetheless, parents worried about the adequacy of funding, particularly in relation to problems they perceived such as staff turnover.

Family-Centered Aspects of Care

One research question for this study asked how parents described the family-centered care elements they experienced in pediatric skilled nursing facilities. In these facilities, organizational effectiveness can include aspects of family-centered care. At least some parents referenced all 11 elements of family-centered care agreed upon in the literature, although they used different language. Parents most frequently referred to seven of the elements: (a) Parent/Professional Partnerships; (b) Sharing Complete Information; (c) Family as the Constant in the Child's Life; (d) Facilitation of Peer Support; (e) Emotionally Supportive Programs; (f) Incorporating Family Developmental Needs; and (g) Respecting Different Methods of Coping.

Parent/Professional Partnership in the Child's Care

Parents' participation in decisions about their children's care was an element in negotiating complementary care, which directly influenced their satisfaction. The accepted understanding of this element reminds health care professionals that parents have a right to information and meaningful participation in planning and decision-making in their children's care. Parents and professionals may contribute different information and insights, but both are necessary for the care of the child; collaboration is imperative for optimum care.

Parent/professional partnership as an ideal was strongly supported by the data from this study. However, there were several barriers to its becoming a reality.

Parents hold the moral authority and responsibility to make decisions for their child. They exercise their authority for care decisions through personal, participatory, or vicarious control (Zaner & Bliton, 1991). When parents admit their child to a pediatric skilled nursing facility, they do not abdicate their authority. Rather, they must negotiate details of decision-making with the facility which will have physical custody of the child; at that time, parents often alter their decision-making to that of participatory, rather than personal, control. Like Corporate Members, they hold "reserved powers" for decisions after obtaining others' inputs and recommendations. However, parents' descriptions of the negotiation process suggested that the facilities may at times assume that the decision-making authority becomes theirs, rather than remains with the parents. Although most parents described participating in regular care planning meetings, episodic conferences in person or over the telephone, and Individual Education Plan conferences with special education staff, several parents described struggles getting the facilities to "allow" them to participate in decisions. Parents expected the facility staff to welcome and respect their knowledge, insights, and ideas about the care of their children and to exchange their own ideas as partners in the child's care. However, there was an imbalance of power: the facility had the physical custody of the child; parents held the decision-making authority, but had little leverage because pediatric nursing facilities were scarce and parents had no alternatives for their children's care.

Sharing Unbiased, Complete Information

This element is understood to mean that all possible information about the child is shared between parents and professionals in a timely way and in a mutually understood language that contributes to all parties being empowered to make informed decisions regarding the child's care. Regular, accurate, and timely communication between parents and facility staff was a crucial aspect of parents' negotiating complementary care. The facility's initiative in contacting parents to exchange information or to consult with them indicated the staff's respect and understanding that the parents remained the child's parents with their moral authority for decision-making. However, several parents described their reluctance to share information in the form of negative feedback to the facilities; they felt vulnerable and feared losing the facility as a resource if the staff became angry with them.

Family as the Constant in the Child's Life

Parents used the terminology, "maintaining our child as part of our family." The professionally accepted understanding of this family-centered care element counsels health care professionals to recognize, support, and respect the stable, key role families have in their children's care, while health care systems and personnel fluctuate. As such, this element relates to parental decision-making. However, it also relates to maintaining the identity of the family that will continue to be the constant in the child's life.

Most parents identified one of the facility's major tasks as assisting families to retain their sense of family, helping families to incorporate the child in care as well as other members. Parents looked for family-oriented activities sponsored by the facility, parent involvement in care decisions, and facilitation with the logistics of home visits.

Encouragement of Peer Networking and Support

This family-centered care element is understood to mean the facilitation of parent-to-parent support. Health care professionals who are not parents of medically fragile children can understand parents' experiences only vicariously. The understanding and support of another parent uniquely reduces the parent's sense of isolation. Most parents in this study described their isolation. Facilitation of parental support was an indicator of satisfaction.

Emotionally Supportive Policies and Programs

This label refers to part of a family-centered care element that includes financially supportive policies as well. Providing emotional support is understood to mean developing multi-dimensional policies and programs that assist with the psychosocial needs of families with children who have special health care needs. The families in this study described their needs in the areas of parent and sibling support.

Parent support. Parents' focus typically was primarily on their children's care. However, they also recognized their own sense of isolation and need to establish supportive connections with facility staff as well as with other parents. The facility's ability to assist parents to develop supportive connections had a direct effect on families' levels of satisfaction with care. The facility staff's understanding of the emotional burden parents carried, sensitivity to their needs, asking about rather than assuming their emotional state, withholding judgment, talking to them about their children, facilitating their meeting other parents, and sincerely inquiring about their lives contributed to a reduction in parents' sense of isolation and the establishment of supportive connections.

Sibling support. Most parents in this study had other children in addition to the one admitted for care. Often, parents were puzzled and distressed by the siblings' relationships with the child in care. Because they usually did not know other families with medically fragile children, they had few role models and seldom had advice from experienced persons. A few families described the helpfulness of the assistance with sibling issues they received from facility staff. Families identified several ways in which facilities could assist families with siblings, including a welcoming, hospitable attitude, assistance with understanding sibling development and responses, provision of appropriate family visiting space, and age-appropriate activities for siblings while visiting.

Welcoming, hospitable attitude. Parents repeatedly referred to looking for evidence of a welcoming, hospitable attitude on the part of the facility. Parents were sensitive to whether the tone of the facility spoke to welcoming their child, themselves, siblings, and extended family members, to the ease of entry and visiting policies, and to the decor and furnishings of the entrance and visiting areas. Parents looked for a welcoming attitude in the ways the facility staff dealt with personalization of their child's space and disruption of the unit by visitors. They wanted the facility staff to view their families as an important part of their children's lives, and not merely an inconvenience or bother to the facility.

Incorporating Families' Developmental Needs

This family-centered care element recognizes that healthy family functioning is promoted by enabling the child and family to meet developmental tasks. In this study, parents described a need for assistance with understanding the developmental tasks of siblings, particularly as they related to the medically fragile child. The element corresponds with the parental indicator of sibling support. While designing their ideal facility, parents also requested anticipatory guidance regarding the developmental stages of the child in care, particularly as they experience puberty and sexual development.

Recognition of Family Strengths and Individuality and Respect for Different Methods of Coping

This family-centered care element is understood to mean that family strengths and resources must be considered in assessing and addressing family needs, and that different methods of coping must be respected and supported. This element was remarkable in its negative implications for families of medically fragile, severely neurodevelopmentally impaired children who have concluded that their families' needs are best met by out-of-home care for their children.

The researcher returned to the literature after analyzing parents' descriptions of their families' desperate situations prior to the children's nursing home admissions. Most book and journal articles discussing nursing homes or chronically ill children were silent about children who required nursing home care. The authors discussed formidable family burden, the need for social support, financial burden, long-term adaptation, and the stressors of providing in-home nursing care to medically fragile children but most stopped short of acknowledging nursing home care as an option for families. Where out-of-home care was mentioned, there was often a strong anti-institutional bias (Harrington et al., 1994; Hochstadt & Yost, 1992; Jackson & Vessey, 1992; Perrin, Shayne, & Bloom, 1993).

Certainly, few parents or health care professionals knowledgeable about medically fragile children and their families would disagree that care of children in their own homes is an ideal. The family feels most like a family when all members can interact and function according to personal norms and customs. In their own homes, they can do things their way and individualize their children's upbringing according to their own insights and values. Parents expect to care for their own children; other people expect them to, also; it is considered normal.

Care of a medically fragile, severely neurodevelopmentally impaired child in a nursing facility can be less personalized and less individualized; care is provided by staff on three rotating shifts, rather than continuously by one or two parents. Care is not likely to be implemented always according to the parents' methods, but rather in the manner the caregiver has found to be efficient and effective.

However, parents described their total exhaustion and depletion due to providing 24-hour care on an ongoing basis to their medically fragile child, while attempting to parent other children, nurture a marriage, earn a living, and complete household chores. Their families were stressed to the maximum; parents were unable to attend to their other children adequately; they were unable to rest and sleep because of the amount of care and vigilance the child required; they were reporting to work fatigued and jeopardizing their employment.

The option of caring for the child in a nursing facility can alter the benefit/burden ratio for families. Families can obtain relief from the burden of the child's physical care. The child can receive high quality, loving care in a pediatric skilled nursing facility. Parents can collaborate with health care professionals in planning and deciding about features of their child's care. Parents can negotiate complementary care for their child; establish supportive connections with others who understand their situations; and get their lives back, enabling them to parent their other children and enjoy life's pleasures. In this study, parents related numerous ways in which facilities can increase their sensitivity to families' needs as they provide care, thus helping to change the ratio between the burdens and benefits of pediatric nursing home care.

Quality of Children's Care

Parents' first priority was the quality of their child's care. They described expectations of clinical competence, including knowledge of the child, skilled monitoring, recognition and evaluation of symptoms, prevention of complications, and medically and physically safe environments. Their descriptions of high quality nursing and medical care included therapies, activities, and their children's interactions with a variety of people. Parents' inclusion of therapies, activities, and social stimulation was less by way of substantively altering the child's basic condition than by enhancing the quality of the child's life. Parents looked for evidence of trustworthiness as they observed the staff caring for their children and developed confidence in the quality of care the staff provided.

Although family-centered care implies the characteristic of quality, explicit statements of excellence in clinical care were not found in the literature of accepted key elements of family-centered care. For the families in this study, their child's need for 24-hour skilled nursing care of high quality was the driving force behind parents' decisions to seek long-term nursing care for their children. Therefore, an explicit statement of clinical competence should be added to the list of accepted family-centered care elements. Family-centered care can be delivered without clinical competence; conversely, clinically competent care can fail to focus on the family. Both aspects are essential, however, to high quality care.

Basic Hygiene

It was very important to parents that their children were kept clean, presentable, and attractive. They wanted the children bathed and shampooed frequently, with regular cleaning of faces, mouths, eyes, and ears. They wanted them dressed attractively in the matched outfits most parents provided. The parents ascribed lack of basic hygiene to problems with adequate numbers of trained nursing staff.

Affectionate, Loving Staff

In addition to competent attention to physical and social needs, parents hoped their children would receive affectionate, loving care from the staff. Many parents tearfully explained that a factor that made their child's admission to the facility more bearable was the hope that the facility staff would love their child as they did. Most parents believed that their children did receive care from staff members who loved them.

Implications and Recommendations

The study conceptions, methods, and findings will be evaluated. Implications for theory, practice, and further research will be discussed.

Organizational Theory

Measuring organizational effectiveness by indicators that a specific group of stakeholders considers important is labeled the strategic constituencies perspective (Seashore, 1983). In this study, parents, as constituents of pediatric skilled nursing facilities, selected indicators of effectiveness that relate primarily to the direct care their children receive, rather than to the functioning of the organization as a whole.

The researcher developed an interview guide based on the components of an open system, and included questions related to indicators of the organization's inputs (e.g., sufficiency of resources, responses to environmental change); transformations or internal processes (e.g., team spirit, communication, decision-making); outputs (e.g., goal attainment, satisfaction); context, and feedback effects. The indicators used in the interview guide tended to relate to the organization as a whole. Parents' responses disclosed that some of the pre-selected indicators were important to them (e.g., sufficiency of staff, communication, and decision-making), but that there were many additional indicators which were extremely crucial from their perspective (e.g, clinical competency, affectionate care, basic hygiene, parent and sibling support, maintaining their identity as a family, and organizational and financial stability).

Comparison to Theorists' Indicators

Campbell (1976) extensively examined the literature on organizational effectiveness while attempting to determine the meaning of the concept and appropriate ways of measuring it. He identified 30 distinct criteria that researchers used in assessing organizational performance. The parents in this study readily agreed with some indicators on Campbell's list: turnover, stability, control, quality, and satisfaction. While parents might be indirectly affected by other indicators on Campbell's list, the descriptions of parents' experiences with the facilities did not include references to indicators such as productivity, role and norm congruence, profit, or internalization of goals. When parents are the constituents, they emphasize outputs (products or services; in this case, organizational stability and quality of care provided to child and family). They also stress inputs (acquired resources; in this study, adequate staffing, financial resources, and changes in response to regulatory requirements), transformations (organizational processes such as promoting parent/professional partnerships and facilitating parent-to-parent support), and feedback (evaluative information) but only so far as they are able to see the connection to the output of concern to them--the well-being of their child.

Hall (1987) proposed a model of organizational effectiveness based on multiple goals, resources, decision processes, constituents, and time frames. Because of these multiple dimensions, he suggested that organizations could be effective in some areas while simultaneously being not so effective in others. The results of this study indicate that parents experienced areas of simultaneous effectiveness and ineffectiveness within the facilities. For example, parents considered the facilities as effective, providing high quality care, caring about the child and family, helping the family to stay involved with the child, including the parents in decision-making, providing timely communication, and demonstrating team spirit. At the same time, there were several areas which did not adequately meet the needs of the children in care and their families, for example, frequent staff turnover, basic hygiene, organizational instability, parent and sibling support, and insufficient explanations to parents about funding mechanisms and regulatory requirements.

In this study, parents' descriptions of their experiences with the facilities provided a first glimpse of the organizations from their perspectives. The value parents ascribed to their definition and their indicators of the organization's performance could provide the basis for building a cumulative body of knowledge to guide pediatric skilled nursing facilities.

Organizational Culture

Denzin (1989) held that the social sciences are mandated to clarify and understand the experiences and perspectives of the people whom they serve, in order to design programs that are effective. Key leaders who regard parents as constituents and who hold their perspectives as important will be needed in the pediatric skilled nursing facilities if changes in programs and policies are to be made in response to the findings of this study. Organizational leaders can use the parent generated indicators to monitor effectiveness in their facilities and to improve their services. Parents' awareness of leaders' strong influence was reflected in their expressed desire to be involved in the selection of the head nurse and in their dependence on key nursing staff for inclusion in decision-making about their child.

Parents described what they valued in the facilities caring for their children and what contributed to their satisfaction with care. As constituents within the organization, however, parents functioned at a disadvantage in the balance of power. They were acutely aware that they were utilizing a scarce resource for their children and that their alternatives were few to none. One might argue that when vulnerable populations have little choice, facilities have a greater responsibility to provide optimum care than when preference can be exercised.

The parents in this study observed significant changes in health care delivery systems over the past few years. Local and national health care systems, even those long established and usually stable, conveyed images of accelerated change as they closed divisions and formed new alliances. Parents' awareness of the rapid mergers and closures in today's health care environment was reflected in their expressed need for organizational stability and their concerns about having skilled nursing resources for their children today and into the future, particularly as their children survived through their teens. In these times of scarce health care resources, facilities can assure families that they have strong, committed leaders willing to risk established patterns of success and to create new ways of securing necessary funding for needed programs.

Nursing Practice

Parents related facility practices that helped promote experiences leading to satisfaction with care, and those that did not. In general, parents found it helpful to interact with staff who acknowledged and respected parents' roles, were empathetic, sensitive, and understanding even when a situation could not be changed, who included parents in decision-making, and welcomed the families' participation in facility activities with the attitude that the staff were there to work together with parents for the child's best care. Parents appreciated receiving anticipatory guidance from facility staff, so that they were better able to plan ahead for milestones in their families' lives. They valued truthful and timely information that was as complete as possible.

Other practices hindered satisfactory experiences and increased parents' stress. These included inadequate or incompetent staffing, staff failing to take the time or make the effort to get to know the family, staff assuming without verification that they knew what parents were feeling or what was best for a particular family, and staff being insensate or oblivious to what parents felt.

Parent satisfaction was achieved through their successful negotiation of partnership with staff for their child's care; establishment of supportive relationships among facility staff and other parents, as well as friends and relatives outside the facility; and "getting their lives back." Many practice recommendations flow from parents' perceptions of problems of organizational effectiveness. Some recommendations can be implemented immediately; others require longer-range planning and budgeting. Implementation of many of the recommendations requires that strong organizational leaders be convinced of their benefit and nurture an organizational culture which supports these changes.

Staff Sensitization and Education

As a result of this study, facility staff could be educated and sensitized to increase their understanding that parents may experience ambivalent feelings, and that this experience may continue throughout the child's life. Staff can be encouraged to listen to parents to discover what they are feeling; careful listening will help parents express breadth and depth of feelings. Parents are better able to move forward if seemingly conflicting feelings are accepted without judgment (Jacob, 1993, p. 343).

Parents' reports of their experiences can sensitize facility staff to the burdens of guilt, worry, and watchfulness that parents carry. The organization can work to increase staff appreciation of parents' ongoing sense of responsibility for assuring the best care possible for their child and for intervening when they believe it to be necessary. Staff can help lighten parents' burdens by practices such as phoning parents or approaching them when they visit, taking opportunities to keep parents well informed by explaining what they are doing for the child and why, and articulating their statements in ways least likely to generate anxiety. Staff can be encouraged to understand that even though parents have a sense of being at risk for losing their child's care, they often feel obliged to question, and that questions can be different from criticism.

Parents hope for quality care that is loving. Staff can be sensitized to the importance of such care to parents. Staff can realize that verbalizing their knowledge of and affection for the children pleases parents, so long as facility staff keep in mind that they do not replace the child's parents. Through increased communication about the quality of the child's care and the affection with which it is given, both parents and staff may experience greater satisfaction.

Families have different circumstances and needs. Staff can be encouraged to recognize individual differences. They can be sensitized to inquire of parents what is helpful to them, and to respond with a welcoming and accepting attitude in areas such as individual preferences for handling the child's personal belongings, quiet or active visiting space, or activities that promote family togetherness.

Promote Consistent Family-Centered Practice

One means of promoting consistent practice in the facility is the development of written policies and procedures. These convey the organization's official position regarding issues and transmit the organization's culture. Written policies and procedures also convey concepts of both family and facility rights and responsibilities.

Based on the results of this study, written policies and procedures could include a commitment to adequate numbers of consistent, competent staff; statements of non-retaliation for parental negative feedback to the facility; conditions under which a child may or may not be discharged from a facility; statements recognizing parents' moral authority for decision-making regarding their children and parent/professional partnerships for care; measures for conveying welcome and hospitality to families; and processes for linking each family with a key staff member liaison, designating primary responsibility for communications with parents.

Strengthen Staff Recruitment, Orientation, and Retention

The results of this study suggest that pediatric skilled nursing facilities may be able to improve the quality of care of the children, support the mental health and sense of well-being of the families they serve, and increase families' satisfaction with care by strengthening recruitment and retainment strategies to assure the quality and longevity of their staff, particularly but not exclusively, the direct care staff. Facility administrators and third-party payers will no doubt struggle with the financial implications of this recommendation. Although this study was not intended to explore cost comparisons, an argument can be made that strengthening the quality and continuity of the facility staff is also an investment in the contribution to society by the healthy families of the children in care.

Gaps in staffing schedules are difficult to fill; staff often work part-time and on-call positions only until they find a permanent position. The three metropolitan-area pediatric skilled nursing facilities could consider reducing expenses through collaboration on recruitment and orientation of direct care staff. They might also collaborate in the creation of an on-call pool of oriented, skilled staff to eliminate the need to employ agency staff who are unfamiliar with the particular needs of medically fragile children.

Assist Families with Transitions

In this study, parents reported that their anxieties about their children's care soared when there was a turnover in direct care staff. Facilities can help parents during staff transitions by notifying them in advance that their child's regular caregiver will be leaving so they can prepare for the change and achieve closure with that person. For example, charge nurses could introduce parents to new caregivers working with their child, rather than having parents find strangers in the room. Nurses could review the new staff member's experience and explain the orientation process to become familiar with their child. New staff members could be oriented using a mentor or buddy system with an experienced staff person who knows the individual children well. Several parents in the study requested a regular newsletter or bulletin board for parents, to inform them of staff changes and new staff members' names.

Many families in this study described their struggles accessing information about resources for their children. There was no single person or agency they contacted that directed them to the needed resource. For most families, there was little help available to them for understanding the burdens they carried, assisting them in analyzing and weighing the needs of the entire family, and encouraging them. The descriptions of family struggles point out the need for a central clearinghouse of information and referral, perhaps on a Web site. The researcher's experience nationally with parents seeking information about availability of resources also supports this need. In addition, family difficulties in obtaining information illustrated the need for better dissemination of facility programs to nurses, physicians, social workers, and other staff working in pediatric acute care, clinics, and agencies where they are likely to encounter medically fragile children and their families.

Strengthen Family Support Programs

Based on the results of this study, each facility could be encouraged to have a sufficient number of social workers to facilitate the usual functions, including the logistics of the pre-admission, admission, and ongoing negotiations with state and federal agencies and paperwork requirements, as well as to orchestrate ongoing therapeutic responses to the psychological and emotional needs of families. The process of admitting a child to the facility relieves families of the physical burden of care, but does not liberate them from the ongoing, unending sense of bereavement, worry, guilt, vigilance, confusion about their children's reactions, and isolation. Because parents' experiences were shown to be dynamic and iterative, staff cannot assume that the manner in which parents and siblings cope today is the same as it was yesterday or will be tomorrow. Families cannot simply be put on "automatic pilot" following the first few days of their child's admission to the facility. They need connections with a significant staff person who establishes an ongoing, supportive relationship with them.

Based on parents' descriptions of "getting their lives back," a reduction in visiting frequency may be a sign of health. A staff member who relates to the parents in depth may be able to help judge the healthiness of the coping or visiting frequency. A social worker, nurse, or other key staff person might be assigned to each family at admission, responsible for connecting with them in-depth and keeping other team members informed of family progress or concerns, perhaps by rotation.

New parents can be facilitated in meeting other parents, who can lessen their isolation in the experience of admitting their child for care. Further research is needed to explore the feasibility of implementing one parent's suggestion pairing new parents with veteran parents to befriend and guide them. The proposal was well received by other parents in that focus group. The facility staff might want to pair new parents with veteran parents who exhibit overall satisfaction with their child's care, having experienced the iterative processes of negotiating complementary care, establishing supportive connections, and balancing concerns for their medically fragile child with other family responsibilities and pleasures of life.

Some parents expressed an interest in formal support groups for themselves with a variety of topics; several preferred simply to socialize with other parents. A few suggested a separate support group for fathers, perhaps centered on some project. The three metropolitan-area facilities could form a consortium. They could collaborate on encouraging peer support and themselves providing a variety of types of support in different facilities, for example, a sibling support group in one facility; hands-on projects for fathers in another; educational sessions of various topics for parents in a third; sessions for developing strategies in dealing with state and federal bureaucracies; or a wine and cheese social evening for parents. Topics specific to a particular facility would, of course, be restricted to that facility; otherwise, parents from all three facilities could be included in the sessions of their choice. Such a consortium of facilities could collaborate on providing a broader continuum of care, for example, in-home nursing and respite care for medically fragile children at home and skilled nursing care for young adults. A consortium could also provide a strong base for negotiating with the state for reimbursement rates for medically fragile children.

Parents needed age-appropriate activities for visiting siblings after they greeted their brother or sister, while parents lingered with the medically fragile child. Parents also needed guidance for understanding siblings' relationships to the child in care. Many parents requested a support group for siblings only.

Implement Changes Based on Parents' Ideal Facilities

Parents' conceptions of an ideal facility can be regarded as a resource for facilities interested in designing space and improving service. Pediatric skilled nursing organizations can review the parents' design of their ideal facility and implement many of the parents' recommendations immediately as constituent-relevant changes in the organization and delivery of care. Limitations in parents' recommendations can be recognized without hindering their immediate use. Other parental recommendations can be incorporated into longer range planning within the organization.

Research

This study was designed to be descriptive and exploratory because of the dearth of formal studies of pediatric skilled nursing facilities, parents of the medically fragile children receiving care there, parents' perceptions of facilities' effectiveness, or factors contributing to their satisfaction with care. The design allowed the researcher to select sites to maximize access, and to use a purposively selected sample, which provided subjects with rich detail about the research questions; it also permitted the expansion of sampling during the study.

The method selected for data collection permitted the researcher prolonged personal engagement with parents, providing time to establish rapport, build trust, and create an atmosphere in which the parents would freely and openly respond to the questions in the interview guide. The researcher's experience with families of medically fragile children influenced the choice to interview individual parents first, followed later by focus group interviews. Several parents related that they would have been hesitant to participate at an initial focus group session because of the emotional content of the interview. However, gathering parents together after a 4-month interval following the initial interviews allowed the researcher to collect the desired data and also to visualize the effect of empowering participants (Mishler, 1986).

Parents received the researcher's undivided attention for an approximate total of 6 hours each, as they told the stories of their medically fragile children and their families' experience with the pediatric skilled nursing facility. Many parents said they had not discussed these aspects of their lives for years, even with each other. The parents provided abundant in-depth data in response to the interview questions. The copious data that parents provided permitted the researcher to develop thick description to allow judgments about transferability of the study findings to different settings.

The researcher knew some parents from past professional interactions; she encouraged those parents to set aside assumptions about her knowledge of them temporarily while they responded completely to the questions. She assured the parents that she was not currently affiliated with any pediatric skilled nursing facility. With parents whom the researcher did not know prior to the individual interview, she explained that she had a long-standing concern for families whose children needed nursing home care. At the close of those interviews, the researcher revealed her past professional position in a pediatric skilled nursing facility as a way of promoting trust, so that both familiar and new parents would have similar information about the researcher when they came together for the focus group sessions. Because of the researcher's knowledge of families and facilities, however, there were times during the individual interviews when the researcher had difficulty separating the researcher and clinical roles.

The qualitative analysis selected for data analysis allowed the researcher to invoke her knowledge of families and organizations and to focus the parents' stories to the phenomena of interest for this study. By using both pre-established and emergent codes for analyzing the data, the researcher was able to link theoretical and experiential data, leading to recommendations for the manner in which parents and facilities can assist each other.

The focus group method is a strategy that facilities might consider using to bring parents together to gather input regarding a topic such as special projects or facility renovation. In addition to obtaining useful data, the facilities would be promoting peer connections, which parents indicated they need and want. As an example of this, following the focus group interviews and before the end of this study, several parents exchanged information, formed a work group, and began meeting to develop strategies for developing skilled nursing resources for their children approaching young adulthood.

The design and methods selected for this study allowed effective access to sufficient numbers of relevant parents and facilitated prolonged engagement with them for time to develop rapport and trust. The methods enabled the researcher to obtain rich, in-depth data and to link theoretical and experiential data. However, additional research using similar methods may be needed to determine if geographic and other situational variables affect parents' responses.

Because of practical considerations, the sample was restricted to parents whose children were receiving long-term care in Portland metropolitan facilities, who spoke English, visited their children regularly, and were willing to participate in the study. This may limit the generalizability of the findings. It is unclear whether the results would have been different had the study included parents whose children were admitted for respite (short-term) care, who did not visit their children regularly, who were reluctant or unwilling to participate in the study for whatever reason, who were non-English speaking, or whose children received care in a different state. A similar study could be done in a different geographical region where pediatric skilled nursing facilities are located, such as New England, New York, or the Midwest, to determine whether the researcher asked the right questions and analyzed the parents' meanings appropriately, to see if the results of the study hold true. Additional research could be designed to reach a broader group of parents and to test the relationships among the factors that seemed to influence parents' satisfaction: negotiating complementary care; establishing supportive connections; and getting their lives back.

This study focused on the indicators that parents as strategic constituents selected to evaluate organizational effectiveness. Further research is needed to develop and test indicators of effectiveness that could be used by organizations to measure parents' satisfaction with their performance. These could then be used to measure change before and after an introduction of innovations.

Further studies could elicit important indicators of effectiveness from the perspectives of direct care staff and facility administrators. These additional indicators could augment those of the parents, thus including parental, staff, and administrative perspectives and providing a comprehensive tool for facilities to assess their effectiveness and improve service.

Parents described their experiences in which they adjusted to their children's care in the pediatric skilled nursing facilities by concluding that the facility might not be able to do everything their way ("The facility can't do everything my way"). Further study could explore whether this process is more parental adaptation or capitulation, and what effect there might be on satisfaction.

Parents described that their trust in the facilities and their satisfaction increased over time. However, a couple of parents stated that they had to "make" themselves be satisfied, because they were desperate for a care option for their child. Satisfaction with care affected families' peace of mind and well-being. Further research could explore whether the phenomenon was satisfaction or satisficing, convincing oneself that something is good "enough."

The public policy implications of this study make it imperative that negative popular perceptions of nursing home care for medically fragile, severely neurodevelopmentally impaired children be changed. The study has shown that access to this level of care can profoundly affect the mental health and well-being of the entire family. Publication of these findings in scholarly and popular journals, through newsletters, and through additional research as recommended can contribute to changing perceptions.

Conclusion

This exploratory study resulted in descriptions of parents' experiences with three Portland, Oregon, metropolitan pediatric skilled nursing facilities caring for their children. The study used an open organizational systems framework and a strategic constituencies perspective. The data were coded using two sets of codes: pre-established, theoretical codes and emergent, experiential codes. Emergent codes revealed that parents experienced a dynamic, iterative process with multiple points where facilities can intervene to improve families' outcomes. The results of the study contributed to a theoretical understanding of the relationships among factors that influence parents' satisfaction with care: negotiating complementary care for their children; establishing connections that support siblings and themselves; and getting their lives back. Satisfaction and comfort with their child's care led to peace of mind and well-being for the entire family. Facilities with even limited monies can use the results of this study to provide services which parents identified as important to the satisfaction of their experiences with care.

References

Adams, P. F., & Hardy, A. M. (1989). Current estimates from the National Health Interview Survey, 1988. *National Center for Health Statistics: Vital and Health Statistics, 10(173).* Hyattsville, MD: U. S. Department of Health and Human Services.

Aday, L. A., Lee, E. S., Spears, B., Chung, C. W., Youssef, A., & Bloom, B. (1993). Health insurance and utilization of medical care for children with special health care needs. *Medical Care, 31,* 1013-1026.

Ahmann, E. (1994). Family-centered care: Shifting orientation. *Pediatric Nursing, 20,* 113-117.

American Health Care Association. (1996, July). *Customer satisfaction in long term care.* Princeton, NJ: The Gallup Organization.

Anderson, B., & Hall, B. (1995). Parents' perceptions of decision making for children. *Journal of Law, Medicine & Ethics, 23,* 15-19.

Baine, S., Rosenbaum, P., & King, S. (1995). Chronic childhood illness: What aspects of caregiving do parents value? *Child: Care, Health and Development, 21,* 291-304.

Beckhard, R., & Harris, R. T. (1987). *Organizational transitions: Managing complex change.* Reading, MA: Addison-Wesley.

Bennis, W. G. (1966). *Changing organizations.* New York: McGraw-Hill.

Bleck, E. E. (1992). Disabled children: Care, compassion, charity, costs. *Developmental Medicine and Child Neurology, 34,* 189-190.

Blustein, J. (1993). The family in medical decision making. *Hastings Center Report, 23,* 6-13.

Bolman, L. G., & Deal, T. E. (1991). *Reframing organizations: Artistry, choice, and leadership.* San Francisco: Jossey-Bass.

Bond, N., Phillips, P., & Rollins, J. A. (1994). Family-centered care at home for families with children who are technology dependent. *Pediatric Nursing, 20,* 123-130.

Brown, W., Pearl, L. F., & Carrasco, N. (1991). Evolving models of family-centered services in neonatal intensive care. *Children's Health Care, 20,* 50-55.

Brust, J. D., Leonard, B. J., & Sielaff, B. H. (192). Maternal time and the care of disabled children. *Public Health Nursing, 9,* 177-184.

Budreau, G., & Chase, L. (1994). A family-centered approach to the development of a pediatric family satisfaction questionnaire. *Pediatric Nursing, 20,* 604-608.

Calnan, M. (1988). Towards a conceptual framework of lay evaluation of health care. *Social Science & Medicine, 27,* 927-933.

Cameron, K. (1981). The enigma of organizational effectiveness. In D. Baugher (Ed.), *New directions for program evaluation: Measuring effectiveness*. San Francisco: Jossey-Bass.

Cameron, K. S., & Whetten, D. A. (Eds.). (1983). *Organizational effectiveness: A comparison of multiple models*. New York: Academic Press.

Campbell, J. P. (1976). Contributions research can make in understanding organizational effectiveness. In S. L. Spray (Ed.), *Organizational effectiveness: Theory--research--utilization*. Kent, OH: Kent State University Press.

Casey, A. (1995). Partnership nursing: Influences on involvement of informal caregivers. *Journal of Advanced Nursing, 22,* 1058-1062.

Center for Disease Control. (1995, August 25). Disabilities among children aged < 17 years--United States, 1991-1992. *Morbidity and Mortality Weekly Report, 44,* 609-613.

Cohen, S. (1985). *Statewide service network for chronically ill children and their families*. Unpublished manuscript.

Cohen, W. I. (1995). Family-oriented pediatric care. *Pediatric Clinics of North America, 42,* 11-19.

Cole, M. P. (1990). A parent's view of quality health care. *Maternal Child Nursing, 15,* 371-372.

Connor, P. E. (1980). *Organizations: Theory and design*. Chicago: Science Research Associates.

Cotton, S. D., & Oransky, K. S. (1980). *Systems theory: Movement from a conceptual perspective to a general theory of the family*. (ERIC Document No. ED 201 941)

Council on Scientific Affairs, American Medical Association. (1993, March 10). Physicians and family caregivers. *Journal of the American Medical Association, 269,* 1282-1284.

Coyne, I. T. (1996). Parent participation: A concept analysis. *Journal of Advanced Nursing, 23,* 733-740.

Cummings, L. L. (1983). Organizational effectiveness and organizational behavior: A critical perspective. In K. S. Cameron & D. A. Whetten (Eds.), *Organizational effectiveness: A comparison of multiple models*. New York: Academic Press.

Daft, R. L. (1989). *Organization theory and design*. St. Paul, MN: West.

DeChillo, N., Koren, P. E., & Schultze, K. H. (1994). From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry, 64,* 564-576.

Denzin, N. K. (1989). *Interpretive interactionism*. Newbury Park, CA: Sage.

Diamond, J. (1994). Family-centered care for children with chronic illnesses. *Journal of Pediatric Health Care, 8,* 196-197.

Donabedian, A. (1988). Quality assessment and assurance: Unity of purpose, diversity of means. *Inquiry, 25,* 173-192.

Dunst, C. J., & Trivette, C. M. (1996). Empowerment, effective helpgiving practices and family-centered care. *Pediatric Nursing, 22,* 334-337.

Etzioni, A. (1964). *Modern organizations*. Englewood Cliffs, NJ: Prentice-Hall.

Evan, W. M. (1976). Organization theory and organizational effectiveness: An exploratory analysis. In S. L. Spray (Ed.), *Organizational effectiveness: Theory-research-utilization*. Kent, OH: Kent State University Press.

Foley, G. V. (1993). Enhancing child-family-health team communication. *Cancer, 71* (Suppl. May 15), 3281-3289.

Furse, D. H. (1983). Who are the real nursing home consumers? *American Health Care Association Journal, 9,* 51-54.

Gale, C. A. (1989). Inadequacy of health care for the nation's chronically ill children. *Journal of Pediatric Health Care, 3,* 20-27.

Georgopolos, B. S. (1986). *Organizational structure, problem-solving, and effectiveness*. San Francisco: Jossey-Bass.

Goldman, A. E., & McDonald, S. S. (1987). *The group depth interview.* Englewood Cliffs, NJ: Prentice Hall.

Gortmaker, S. L., & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. *Pediatric Clinics of North America, 31,* 3-18.

Grant, N. K., & Hrycak, N. (1987). Use of the critical incident technique to elicit the opinions of residents of long-term-care facilities about their care. *Nursing Homes,* ,38-44.

Haas, D. L. (1992). Historical overview of the development of family-centered, community-based coordinated care in Michigan. *Issues in Comprehensive Pediatric Nursing, 15,* 1-15.

Haas, D. L., Gray, H. B., Jr., & McConnell, B. (1992). Parent/professional partnerships in caring for children with special health care needs. *Issues in Comprehensive Pediatric Nursing, 15,* 39-53.

Hall, R. H. (1987). *Organizations: Structures, processes, and outcomes.* Englewood Cliffs, NJ: Prentice Hall.

Ham, L. M., & Chamings, P. A. (1983). Family nursing: Historical perspectives. In I. W. Clements, & F. B. Roberts (Eds.), *Family health: A theoretical approach to nursing care* (pp. 33-43). New York: Wiley.

Hanson, S. M. H., & Boyd, S. T. (1996). *Family health care nursing: Theory, practice, and research.* Philadelphia: F. A. Davis.

Hargis, W. J., & Quigley, R. (1984). Family-centered care begins with staff. *American Health Care Journal, 10,* 7-12.

Harrington, C., Cassel, C., Estes, C. L., Woolhandler, S., Himmelstein, D. U. (1994). A national long-term care program for the United States: A caring vision. In C. Harrington & C. L. Estes (Eds.), *Health policy and nursing* (pp. 490-507). Boston: Jones and Bartlett.

Harvath, T. A., Archbold, P. G., Stewart, B. J., Gadow, S., Kirschling, J. M., Miller, L., Hagan, J., Brody, K., & Schook, J. (1994). Establishing partnerships with family caregivers. *Journal of Gerontological Nursing,* 29-35.

Hazlett, D. E. (1989). A study of pediatric home ventilator management: Medical, psychological, and financial aspects. *Journal of Pediatric Nursing, 4,* 284-294.

Hobbs, N., Perrin, J. M., Ireys, H. T., Moynihan, L. C., & Shayne, M. W. (1983). *Chronically ill children in America: Background and Recommendations* (Preliminary report of the project, "Public Policies Affecting Chronically Ill Children and their Families.") Nashville, TN: Vanderbilt Institute for Public Policy Studies, Center for the Study of Families and Children.

Hobbs, N., Perrin, J. M., & Ireys, H. T. (1985). *Chronically ill children and their families.* San Francisco: Jossey-Bass.

Hochstadt, N. J., & Yost, D. M. (Eds.). (1991). *The medically complex child.* Philadelphia: Harwood Academic.

Jackson, P. L., & Vessey, J. A. (1992). *Primary care of the child with a chronic condition.* St. Louis: Mosby Year Book.

Jacob, S. R. (1993). Support for family caregivers in the community. In G. D. Wegner, & R. J. Alexander (Eds.), *Readings in family nursing* (pp. 340-344). Philadelphia: J. B. Lippincott.

Johnson, M. A., Morton, M. K., & Knox, S. M. (1992). The transition to a nursing home: Meeting the family's needs. *Geriatric Nursing,34,* 299-302.

Kirschbaum, M. S. (1996). Life support decisions for children: What do parents value? *Advances in Nursing Science, 19,* 51-71.

Kirschbaum, M. S., & Knafl, K. A. (1996). Major themes in parent-provider relationships: A comparison of life-threatening and chronic illness experiences. *Journal of Family Nursing, 2,* 195-216.

Kodadek, S. M. (1979). *Family-centered nursing concepts in pediatric nursing textbooks*. Unpublished manuscript, University of Illinois at the Medical Center, College of Nursing, Chicago.

Kohrman, A. F. (1991). Medical technology: Implications for health and social service providers. In N. J. Hochstadt & D. M. Yost (Eds.), *The medically complex child* (pp. 3-13). Philadelphia: Harwood Academic.

Kotter, J. P. (1978). *Organizational dynamics: Diagnosis and intervention*. Reading, MA: Addison-Wesley.

Kreuger, R. A. (1988). *Focus groups: A practical guide for applied research*. Newbury Park, CA: Sage.

Letourneau, N. L., & Elliott, M. R. (1996). Pediatric health care professionals' perceptions and practices of family-centered care. *Children's Health Care, 25,* 156-174.

Lewis, C. C., Alford-Winston, A., Billy-Kornas, M., McCaustland, M. D., Tachman, C. P. (1992). Care management for children who are medically fragile/technology-dependent. *Issues in Comprehensive Pediatric Nursing, 15,* 73-91.

Lewis, K. P. (1991). Untraditional facilities extend care to young residents. *Provider, 17,* 57.

Luckenbill, M. M. (1988, June). *Children in nursing homes: Parents' perspective on placement of a severely disabled child.* Paper and videotape presented at the meeting of The Association for the Care of Children's Health, Cleveland, OH.

Lumley, J., & Davey, B. A. (1987). Do hospitals with family-centered maternity care policies have lower intervention rates? *Birth, 14,* 132-134.

Maas, M. L., Buckwalter, K. C., Kelley, L. S., & Stolley, J. M. (1991). Family members' perceptions: How they view care of Alzheimer's patients in a nursing home. *Journal of Long-Term Care Administration, 19,* 21-25.

Malone-Rising, D. (1994). The changing face of long-term care. *Nursing Clinics of North America, 29,* 417-429.

Millner, B. N. (1991). Technology-dependent children in New York State. *Bulletin of the New York Academy of Medicine, 67,* 131-142.

Mishler, E. G. (1986). *Research interviewing*. Cambridge, MA: Harvard University Press.

National Health Interview Survey. (1988). National Center for Health Statistics. Washington, DC: Public Health Service.

Newacheck, P. W., & Taylor, W. R. (1992). Childhood chronic illness: Prevalence, severity, and impact. *American Journal of Public Health, 82,* 364-371.

Nord, W. R. (1983). A political-economic perspective on organizational effectiveness. In K. S. Cameron & D. A. Whetten (Eds.), *Organizational effectiveness: A comparison of multiple models*. New York: Academic Press.

Odle, K. (1988). Partnership for family-centered care: Reality or fantasy? *Children's Health Care, 17,* 85-86.

Ott, J. S. (1989). *The organizational culture perspective*. Pacific Grove, CA: Brooks/Cole.

Palfrey, J. S., Haynie, M., Porter, S., Fenton, T., Cooperman-Vincent, P., Shaw, D., Johnson, B., Bierle, T., & Walker, D. K. (1994). Prevalence of medical technology assistance among children in Massachusetts in 1987 and 1990. *Public Health Reports, 109,* 226-233.

Patterson, J. M., Jernell, J., Leonard, B. J., & Titus, J. C. (1994). Caring for medically fragile children at home: The parent-professional relationship. *Journal of Pediatric Nursing, 9,* 98-106.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Pearson, A., Hocking, S., Mott, S., & Riggs, A. (1993). Quality of care in nursing homes: From the resident's perspective. *Journal of Advanced Nursing, 18,* 20-24.

Perrin, E. C., Newacheck, P., Pless, I. B., Drotar, D., Gortmaker, S. L., Leventhal, J., Perrin, J. M., Stein, R. E. K., Walker, D. K., & Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics, 91,* 787-793.

Perrin, J. M., Shayne, M. W., & Bloom, S. R. (1993). *Home and community care for chronically ill children.* New York: Oxford University Press.

Pettigrew, A., Ferlie, E., & McGee, L. (1992). Receptive and non-receptive contexts for change. In *Shaping strategic change* (pp. 267-299). London: Sage.

Pierce, D., & Frank, G. (1992). A mother's work: Two levels of feminist analysis of family-centered care. *American Journal of Occupational Therapy, 46,* 972-980.

Price, J. L. (1972). *Handbook of organizational measurement.* Lexington, MA: D. C. Heath.

Rawlins, P. S., Rawlins, T. D., & Horner, M. (1990). Development of the family needs assessment tool. *Western Journal of Nursing Research, 12,* 201-215.

Revell, G. M., & Liptak, G. S. (1991). Understanding the child with special health care needs: A developmental perspective. *Journal of Pediatric Nursing, 6,* 258-268.

Richardson, M., Student, E., O'Boyle, D., Smyth, M., & Wheeler, T. W. (1992). Establishment of a state-supported, specialized home care program for children with complex health-care needs. *Issues in Comprehensive Pediatric Nursing, 15,* 93-122.

Richmond, T. S., & Craig, M. (1986). Family-centered care for the neurotrauma patient. *Nursing Clinics of North America, 21,* 641-651.

Rosenbaum, P. (1996). Measuring parents' perceptions of care-giving. *Exceptional Parent, 26,* 53-55.

Rushton, C. H. (1990). Family-centered care in the critical care setting: Myth or reality? *Children's Health Care, 19,* 68-78.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8,* 27-37.

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in Nursing & Health, 18,* 371-375.

Scharer, K., & Dixon, D. M. (1989). Managing chronic illness: Parents with a ventilator-dependent child. *Journal of Pediatric Nursing, 4,* 236-247.

Schein, E. H. (1970). *Organizational psychology.* Englewood Cliffs, NJ: Prentice-Hall.

Schein, E. H. (1985). *Organizational culture and leadership*. San Francisco: Jossey-Bass.

Schieber, G. J., Poullier, J. P., & Greenwald, L. M. (1994). U.S. health expenditure performance: An international comparison and data update. In C. Harrington & C. L. Estes (Eds.), *Health policy and nursing* (pp. 28-39). Boston: Jones and Bartlett.

Schlomann, P., & Fister, S. (1995). Parental perspectives related to decision-making and neonatal death. *Pediatric Nursing, 21,* 243-247.

Schneider, B. (1983). An interactionist perspective on organizational effectiveness. In K. S. Cameron, & D. A. Whetten (Eds.), *Organizational effectiveness: A comparison of multiple models*. New York: Academic Press.

Seashore, S. E. (1983). A framework for an integrated model of organizational effectiveness. In K. S. Cameron & D. A. Whetten (Eds.), *Organizational effectiveness: A comparison of multiple models*. New York: Academic Press.

Shaw, J. D., & Whelan, R. E. (1989). QA outcome measures in long-term care. *Journal of Nursing Quality Assurance, 4,* 48-61.

Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1987). *Family-centered care for children with special health care needs*. Bethesda, MD: Association for the Care of Children's Health.

Shelton, T. L., Jeppson, E. S., & Johnson, B. H. (1992). *Family-centered care for children with special health care needs* (Rev. ed.). Bethesda, MD: Association for the Care of Children's Health.

Shelton, T. L., & Stepanek, J. S. (1995). Excerpts from family-centered care for children needing specialized health and developmental services. *Pediatric Nursing, 21,* 362-364.

Simeonsson, R. J., Edmondson, R., Smith, T., Carnahan, S., & Bucy, J. E. (1995). Family involvement in multidisciplinary team evaluation: professional and parent perspectives. *Child: Care, Health and Development, 21,* 119-215.

Smith, S. K. (1992). *Pediatric skilled nursing facilities in the United States: Locations, descriptions, and networks*. Unpublished manuscript, Oregon Health Sciences University, Portland.

Stein, R. E. K., Bauman, L. J., Westbrook, L. E., Coupey, S. M., & Ireys, H. T. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. *Journal of Pediatrics, 122,* 342-347.

Stein, R. E. K., & Jessop, D. J. (1982). A noncategorical approach to chronic childhood illness. *Public Health Reports, 97,* 354-362.

Stein, R. E. K., & Jessop, D. J. (1984). General issues in the care of children with chronic physical conditions. *Pediatric Clinics of North America, 31,* 189-198.

Stein, R. E. K., & Jessop, D. J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science and Medicine, 29,* 769-778.

Stepanek, J. S., & Ahmann, E. (1995). Parent-professional collaboration when hospital visits are infrequent. *Pediatric Nursing, 21,* 466-468.

Stevens, M. S. (1994). Parents coping with infants requiring home cardiorespiratory monitoring. *Journal of Pediatric Nursing, 9,* 2-12.

Stolte, K., & Myers, S. T. (1987). Nurses' responses to changes in maternity care, Part I. Family-centered changes and short hospitalization. *Birth, 14,* 82-86.

Streubert, H. J. (1991). Phenomenologic research as a theoretic initiative in community health nursing. *Public Health Nursing, 8,* 119-123

Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: The chronic illness perspective. *Research in Nursing & Health, 11,* 293-300.

U.S. Congress, Office of Technology Assessment. (1987). *Technology-dependent children: Hospital v. home care: A technical memorandum.* (OTA-TM-H-38) Washington, DC: U.S. Government Printing Office.

Vuori, H. (1994). The many faces of quality. *World Health, 47,* 10-11

Walker, D. K., Epstein, S. G., Taylor, A. B., Crocker, A. C., & Tuttle, G. A. (1989). Perceived needs of families with children who have chronic health conditions. *Children's Health Care, 18,* 196-201.

Washington State Department of Social and Health Services. (1990). *Provision of in-patient skilled nursing care for medically fragile children, Chapter 183, Laws of 1989.*

Weber, M. (1947). *The theory of social and economic organization.* New York: Free Press.

Youngblut, J. M., Brennan, P. F., & Swegart, L. A. (1994). Families with medically fragile children: An exploratory study. *Pediatric Nursing, 20,* 463-468

Zaner, R. M., & Bliton, M. J. (1991). Decisions in the NICU: The moral authority of parents. *Children's Health Care, 20,* 19-25.

Appendix A

Sample Letter of Support and Access Received from Portland Metropolitan Area Pediatric Skilled Nursing Facilities

Facility Name
Address
City, State, and Zip Code
Date

Researcher's Name
Address
City, State, and Zip code

Dear (Researcher's Name):

We at (facility) agree to collaborate with you in your doctoral dissertation research project. You may work with our social workers to identify parents who meet the criteria for your study and invite them to participate.

We understand that prior to scheduling any interview with parents, your proposal must have been approved by your dissertation committee at Oregon Health Sciences University School of Nursing and the Committee on Human Research. We also understand that parents are free to decline to participate in the study.

Our social workers' names are (Name) and (Name). You may reach them at (Phone Number) or (Phone Number), respectively.

Sincerely,

(Signed)
Facility Administrator's Name
Title

cc: Social Worker
Social Worker

Appendix B

Individual Interview Guide

Before Interview

This study is being done to help facilities like [Facility Name] do the best possible job caring for your child. Facilities want to know how they are doing and how they can do better. I will be talking with parents from several facilities. It's very important to hear from you about your experiences of what you found helpful or not helpful in the facility caring for your child. The things you tell me will remain confidential even when they are blended together with what other parents have to say. Although the facilities will eventually know what all the parents as a group have said, there will be no way for other people to know what any particular person said.

After I have listened to what you and other parents have to say, I will blend your comments into major themes and ask you and other parents to see if they make sense to you. Will you be willing to come to another discussion with a small group of 4-6 other parents (total 6-8) in a few months?

Dissertation: Individual Parent Interviews

1. What is it like to be a parent with a child in (Facility Name)? (Context)

2. How did your decision to admit ____________________ (Child) for care come about? (Context)

3. What was important to you when you were considering admitting ____________________ to your pediatric skilled nursing facility? What were you looking or hoping for? How did (Facility Name) match your hopes? (Values, expectations)

4. What were your experiences with (Facility Name) and your child's admission? (Inputs)

5. What have been your experiences around the facility's getting what it needs to do its job, such as staff, funding, donations, equipment, and supplies? Rules and regulations, and responses to changes in regulations? (Inputs)

6. How are decisions made regarding ____________________ (Child)? Do you feel anxious about your child's care when in the facility? After visiting? (Transformations)

7. Among the facility staff, whom do you consider a source of your support? (Transformations)

8. What has been your experience with (Facility Name) and _______________'s siblings?

9. Does (Facility Name) offer participation in parent support groups? If so, what has been your experience with them? (Transformations)

10. What have been your experiences of (Facility Name)'s sense of its identity, its adaptability, problem-solving, team spirit? What do you experience as the organizations's major tasks? (Transformations)

11. How has (Facility Name) helped you reach your own goals? Has it done what it says it will? Have you experienced conflicting or clashing goals within the facility? If so, how are those handled? What is your experience of the facility's sense of its mission? (Outputs)

12. Some parents have told me that not all parents, and particularly fathers, maintain contact with their children in the facility. Based on your experience, what is it that helps you maintain involvement with your child? Are there things that the facility does or can do to help or hinder this?

13. What has been your experience of employee satisfaction? Parent satisfaction, including your own? (Outputs)

14. Have you felt valued as parents and as part of a team? What has been your experience in giving feedback to the facility? Have you experienced the facility as open to new ideas? (Feedback effects)

15. Based on your experience, is there a way you think you and other parents might give feedback to the facility on an ongoing basis, either about your child's care or other issues in general? (Feedback effects)

16. What advice would you give other parents? (Feedback effects)

17. What has been your experience with the facility's growth? Have you ever worried whether it would survive? (Outputs)

18. What advice would you give the facility for how it could continue or improve? (Feedback effects)

19. Is there anything else you think it would be helpful for me to know about your experiences as a parent at (Facility Name)? (Validity of data)

20. Complete demographic data, which includes information about family and child. [Context])

Appendix C

FOCUS GROUP WORK SHEET

Some of us find it helpful to think about things ahead of time. These are some areas we will focus on at our group meeting.

Each of you would prefer to be able to care for your child at home. However, we know that is not possible at this time. With that in mind, at our focus group session, I will ask you to share the features that you consider to be the most important if you were designing your ideal skilled nursing facility for your child. There are several of you, so I hope there will be a variety of responses and a good discussion of ideas. Please bring this worksheet with you to the focus group session.

FEATURES RELATED TO THE FACILITY'S ENVIRONMENT

1. ____
2. ____
3. ____
4. ____
5. ____

FEATURES RELATED TO THE FACILITY'S PROGRAM OF CARE

1. ____
2. ____
3. ____
4. ____
5. ____

FEATURES RELATED TO THE ORGANIZATION PROVIDING CARE

1. ____
2. ____
3. ____
4. ____
5. ____

Appendix D

Dissertation: Demographic Data

1. Identification
Child's First Name ____________________
Gender ____________ Age (in years) ____________
Length of Stay ________ Date of Admission ____________
Mother's First Name ____________________
Maternal Step-Parent (First Name) ____________________
Father's First Name ____________________
Paternal Step-parent (First Name) ____________________

2. Location
Mother's Distance (in miles) from Nursing Facility:
____
Father's Distance (in miles) from Nursing Facility:
____

3. Age
Mother's Age ____________ Step-parent's __________
Father's Age ____________ Step-parent's __________

4. Ethnicity (Cauc; Afr-Amer; Hispan; Asian; Native Am; Other)
Mother's ____________ Father's ____________

5. Marital Status
Parents' marital and living status ____________________
____
Number of years married/re-married ____________________

6. Educational Level (# years: 8th gr; GED; H. S. grad; college)
Mother's ____________ Father's ____________
Step-parent(s) ____________________

7. Employment Status/Position
Mother's ____________ Father's ____________
Step-parent(s) ____________________

8. Annual Income (Categories best reflecting total annual household income: <$11,000; $11-20,999; $21-49,999; $50,000+)
Mother ____________________
Public Funding for family? ____________________
Father ____________________
Public Funding for family? ____________________
Child's funding source____________________

9. Previous Experience with Formal Organizations (Volunteer, Board, etc.)
Mother____________________
Father____________________
Step-parent(s)____________________

10. Siblings (Names & Ages)
In Mother's Home____________________
In Father's Home____________________
Living Elsewhere____________________

11. Medically Fragile Child
Diagnoses____________________
____
____
Age at Onset __________ Age at Admission to PSNF __________
Hospitalizations before Admission to PSNF (Number and length)
____
____
Length of time (if any) Cared for at Home____________________
Nursing Needs at Time of Admission to PSNF ____________________
____
____
____

12. Other Relevant Demographic Information
____
____
____

Appendix E

Oregon Health Sciences University

Consent Form

Individual and Focus Group Interviews

TITLE: Medically Fragile Children in Pediatric Skilled Nursing Facilities: Parents' Experience of Care

PRINCIPAL INVESTIGATOR:	Celia Capuzzi, RN, PhD	494-7817
CO-INVESTIGATOR:	Sister Katherine Smith, RN, PhC	235-8215

PURPOSE:

You are being asked to participate in this research study because you have a child that is cared for in a skilled nursing facility. The purpose of this study is to learn about you and your child's experiences in the facility. We hope that the information gained through our discussions and the questionnaires that you will complete will lead to better care for children in skilled nursing facilities.

PROCEDURES:

You will be asked to participate in two different activities for this research study: one individual interview, lasting about 2 hours; at a later date, one focus group interview which includes other parents, also expected to last about 2 hours. This research study is expected to take 6-8 months to complete.

Individual interview. You and I will meet for approximately 2 hours, to talk about your experiences since your child was admitted to the nursing facility. I will use an interview guide to ask questions about various aspects of your child's facility. I will also ask you questions using a demographic questionnaire that includes questions such as your child's age and gender and your marital status. For this interview, we can meet in a quiet location of your choice, such as in your home or in your child's nursing facility. Although the interview is expected to take approximately 2 hours, we can take as long as you like. Please use only your first name during the interview, in order to protect your confidentiality. I will tape record our talk, so I can later review what we said. I will also take notes while we talk, but I will not identify you by last name on the tapes or in my notes. When I write about the interview, I will use initials and will not identify you with a particular facility.

Focus group interview. Approximately 3 to 4 months after my individual interview with you and after I've completed interviews with several other parents whose children are in nursing facilities around Portland, I will ask you to meet with 6-8 parents in a group. I will tell you what I've found and ask if that sounds like what you experienced. At that discussion, I will ask another person to help me with tape recording and taking notes, so that I can help make sure that parents get the opportunity to speak. Again, please use only your first name. For this session also, I will not identify you by last name on the tapes or in notes, and will use only initials in the write-up. I will not identify you with a particular facility.

RISKS AND DISCOMFORTS:

There should be no physical discomfort to you from helping with this study. You might have some emotional upset remembering past events if they were difficult. If you feel as if you need follow-up, I will be glad to suggest a resource.

BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit parents in the future.

ALTERNATIVES:

You may choose not to participate in this study, and you are free to drop out at any time. Your child's care will not be affected by your decision whether or not to participate in this study.

CONFIDENTIALITY:

We will use only your first name during the interviews. Only the professional transcriber and I will see your first name; after the first transcription, only your first initial will be used. Neither your name nor any other identifying information will be used for publication or publicity purposes. You will not be identified to your child's facility. During the study, I will keep the audiotapes, transcriptions, and demographic questionnaires in a locked file, accessible only to me. Upon completion of this study, I will destroy the audiotapes. I will retain the transcripts and demographic questionnaires for possible further analysis, maintained in a locked file to which only I will have access. In a separate log, I will keep the names, addresses, and telephone numbers of those parents who have indicated willingness to be contacted at a later date for future possible analysis of the data.

According to Oregon Law, suspected child or elder abuse must be reported to appropriate authorities. If I am concerned about anything you tell me, I will discuss it with you.

COSTS:

You will be expected to provide transportation for yourself to and from the interviews. We expect that there will be no other costs to you as a result of this study.

LIABILITY:

The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self insured for liability claims. If you suffer any injury from this research project, compensation would be offered you only if you establish that the injury occurred through the fault of the University, its officers or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please call the Medical Services Director at (503) 494-6020.

PARTICIPATION:

I will be glad to answer any questions you may have about this study. My phone number is (503) 235-8215. Dr. Celia Capuzzi, PhD, (503) 494-7817, has also offered to answer your questions. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences University.

Your signature below indicates that you have read the foregoing and agree to participate in this study. A copy of this form will be given to you. If you should withdraw from the study, your own unique viewpoint and experiences would be lost. It is very unlikely, but there might be some circumstances that would make the investigator need to remove you from the study.

I am willing to participate in: _____Individual Interview

_____Focus Group Interview

(Please check one or both)

I am willing to be contacted at a later date for future possible analysis:

__________ Yes __________No, I decline

I would like to receive a copy of the results of this study:

__________Yes __________No, not necessary

____ ______________
Subject's Signature Date

____ ______________
Witness Date

____ ______________
Investigator Date

____ ______________
Co-Investigator Date

Appendix F

Pre-established Data Analysis Codes

IA: Codes Related to the Organization's Effectiveness or Ineffectiveness

Open System:

IA-1: Context
Descriptions of, or references to, the context of family's experience with Pediatric Skilled Nursing Facility, such as how the decision came about and what it has been like.

IA-2: Values, Expectations
Descriptions of, or references to, family's hopes and expectations for child's care.

IA-3: Inputs
Descriptions of, or references to, inputs to the organization, such as obtaining resources e.g., patients, funding, & staff; environmental scanning; responses to environmental changes.

IA-4: Transformations
Descriptions of, or references to, organization's internal processes: e.g., decision-making; team spirit; sense of identity; adaptability; problem-solving; communication; support.

IA-5: Outputs
Descriptions of, or references to, organization's outputs, such as achieving goals; sense of mission; parent and employee satisfaction; growth and survival.

IA-6: Feedback Effects
Descriptions of, or references to, processes of providing feedback to the organization.

IB: Codes Related to Family-Centered Care Elements

IB-1: Family as Constant
Descriptions of, or references to, the family as having a pivotal role in the child's life.

IB-2: Collaboration/Partnership

Descriptions of, or references to, family and professional collaboration or partnership. Includes communication and information-sharing; establishment of trust; education & support of both parents and staff; autonomy; fulfillment of expectations; negotiation; balance of power; decision-making agency; evolution over time. Implies mutual respect, understanding of parents' and professionals' roles, and interdependency.

IB-3: Sharing Information

Descriptions of, or references to, the ongoing, open, unbiased, complete exchange of information, ideas, and concerns between parents and professionals caring for their children.

IB-4: Family Diversity

Descriptions of, or references to, recognition and respect for the diversity of families without predetermined assumptions.

IB-5: Coping Methods

Descriptions of, or references to, respect for diverse methods families use for coping with challenges.

IB-6: Peer Support

Descriptions of, or references to, the encouragement of peer networking and support.

IB-7: Developmental Needs

Descriptions of, or references to, incorporating children's and families' developmental needs into families' care.

IB-8: Service Coordination

Descriptions of, or references to, flexible, accessible, and comprehensive mobilization of resources responsive to family needs.

IB-9: Appreciating Families

Descriptions of, or references to, the appreciation of children as imbedded in families who have many concerns and priorities, which may at times take precedence over the medically fragile child's condition.

IB-10: Supportive Policies and Programs

Descriptions of, or references to, policies and programs that support families emotionally and financially.

II: Codes Related to Facility Strengths and Weaknesses

IIA-1: Facility Strengths

Descriptions of, or references to, parents' identification of facility strengths.

IIA-2: Facility Weaknesses

Descriptions of, or references to, parents' identification of facility weaknesses.

IIB: Parents' Most Important Organizational Features

Descriptions of, or references to, parents' identification of what they consider the most important organizational features.

III: Codes Related to Factors Affecting Parents' Satisfaction

III-1: Parents' Satisfaction with Care

Descriptions of, or references to, parents' expressions of satisfaction with care.

III-2: Parents' Dissatisfaction with Care

Descriptions of, or references to, parents' expressions of dissatisfaction with care.

IV: Codes Related to Parents' Perceptions of Ideal Facilities

IV-1: Parents' Recommendations for Improving Care

Descriptions of, or references to, parents' expressions of improvements in the facilities.

IV-2: Features of Ideal Organization

Descriptions of, or references to, features which parents perceive as most important in an ideal pediatric skilled nursing organization.

Appendix G

Focus Group Interview Guide

These groups will consist of 6 to 8 parents who have been grouped so that several facilities are represented within each set. Married couples will be assigned to the same group, unless a different request is made. Separated parents will not be included in the same group.

Before Interview

Good evening (afternoon). As you know, I am doing a study that will help facilities like the ones caring for your children to do the best possible job. Tonight we are going to talk about what all the parents (insert the number of individual interviews) have told me about their experiences with their children in pediatric skilled nursing facilities. We will focus on how other parents' experiences sound and feel like yours. You may have experiences you'd like to add. You will also have the opportunity to discuss how you would design the "ideal" pediatric skilled nursing facility.

Your confidentiality is important, so you won't be identified in this study. Everybody's comments have been put together so that no one story stands out. I will do the same things with tonight's comments, so please be honest and candid in what you say.

I want to be able to pay close attention to what you are saying, so (introduce assistant) is with us tonight to help me tape record our conversation as well as make a few notes while we discuss. Please feel free to speak when you have something you'd like to say, but please speak one at a time.

I'd like you to introduce yourselves briefly, using your first names only, so that we can talk more easily within the group. Please tell us your name and your child's name and age (Goldman, 1987).

Dissertation: Focus Group Interviews

1. Other parents related experiences regarding their children's admission to the facilities, to the way they see things functioning while their child is there, how the facility cares for them and their child, how they provide feedback to the facility and what happens as a result.

   Review themes that emerged from individual interview data. . . .

2. As themes are presented, please indicate whether they reflect your own experience; whether they ring "true" to you.

3. Are there experiences that you remembered when you listened to the themes, but felt we did not quite capture yet? Please share these.

4. If you could have anything you wanted in a pediatric skilled nursing facility for your child, how would <u>you</u> design it? How would it care for your child and your family?

Please share the ideas you brought on your focus group work sheets. We will go around the room in a "Round Robin. " When each person has a chance to share, we can add new ideas and discuss everybody's ideas. You will have an opportunity to indicate your most important ideas by marking them with a colored adhesive dot on the newsprint later in the evening.

Thank you for your participation in this study. When it is completed, I will send you a written summary of what you and other parents indicated would help pediatric skilled nursing facilities do the best possible job caring for your children and your families.