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PROTECTIVE CARE: MOTHERING A CHILD DEPENDENT ON  
PARENTERAL NUTRITION

by

Lorie H. Judson, MN, RN

A dissertation presented to the  
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE  
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the  
requirements for the degree  
DOCTOR OF PHILOSOPHY IN NURSING

May 2002

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## PROTECTIVE CARE: MOTHERING A CHILD DEPENDENT ON PARENTERAL NUTRITION

### Abstract

Home care of technology-dependent infants and children has become an accepted and expected consequence of higher survival rates among critically ill newborns and children who develop chronic illnesses. One of the high-tech modalities which foster dependence of these infants and children is parenteral nutrition. Parenteral nutrition, also called total parenteral nutrition (TPN), supplies life-sustaining nutrients through a central venous catheter and requires the use of machinery to pump this fluid directly into the bloodstream. Due to the tremendous cost of prolonged hospitalization for these children, and the deleterious effects to the child, home care is considered an obvious and viable alternative. It is the mother who feels the impact of care.

The purpose of this study was to examine the role of mothering a child dependent on parenteral nutrition. Nineteen mothers ranging in age from 19 to 54 years were asked to respond to open-ended questions. The resulting transcriptions were analyzed using constant comparative methodology to formulate a grounded theory.

Protective Care emerged as the basic social process, which characterizes the ways these mothers safeguard the lives of the children in their care. Six categories explaining the antecedents, strategies and consequences of Protective Care were found. These are: (a) gaining control, (b) watching over, (c) challenging the system, (d) promoting normalcy, (e) putting life in perspective and (f) celebrating the positive.

These mothers sought to gain control of the situation, by learning and organizing the child's care. Their lives became consumed with the care of the child. They fought for

reimbursement and issues related to home health care and schooling. Despite the challenges presented in the technological role they must assume in their mothering role, these mothers sought to promote normalcy in the child. Putting life in perspective allowed these mothers to maintain this intense role. Finally, they celebrated the positive aspects this child had brought to their lives.

Further research is needed in this population to refine the theory and to examine cultural differences in the role. Instrument construction using reliable indicators could be developed to facilitate intervention studies.

## DEDICATION

To my mother and father  
who challenged and taught me

## Acknowledgements

One can never accomplish a project such as this without the help and support of many people. I would like to begin by acknowledging the chair of my committee, Dr. Patricia Roth. Her expertise as a professor and researcher were invaluable to my education. In addition, she anticipated my moods and reactions to each phase of writing and gently guided me carefully through each one with her well-chosen words of critique and praise. The members of my committee contributed their strengths for which I am grateful. Dr. Fely dela Cruz provided her literature review guidelines, important editing skills and sharpened my writing ability. Dr. Colette Jones offered important perceptions of mothering from her own body of research to complement my observations.

I owe a huge debt of gratitude to my best friend, Judy Papenhausen. She gave me the confidence to begin, her time and help when I needed it most, and the encouragement to continue until completion, never once doubting the outcome.

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## TABLE OF CONTENTS

CHAPTER	Page
I. FOCUS OF THE INQUIRY.....	1
Lines of Inquiry.....	5
Theoretical Underpinnings of Methodology.....	6
Significance of the Study.....	7
II. CONTEXT OF THE INQUIRY.....	10
Medical Technology and the Care of Children.....	10
Historical Aspects of Technology and the Newborn.....	12
Evolution of High Technology for the Newborn.....	15
Technology and Nutritional Support.....	18
Contributing Factor: Short Bowel Syndrome.....	18
Total Parenteral Nutrition.....	20
Perspectives of Mothering.....	21
Social Expectations of Mothering.....	22
Mother- Infant Attachment.....	25
Feeding as a Maternal Behavior.....	27
Mothering a Chronically Ill Child.....	29
Issues of Caregiving and Family Stress.....	29
Care of the Chronically Ill Child.....	31
Home Care of the Technology Dependent Child.....	33

	Critique of the Literature.....	38
III.	<b>METHODOLOGY</b> .....	40
	Grounded Theory.....	40
	Research Strategies.....	41
	Participant Inclusion Criteria.....	41
	Entrée.....	41
	Protection of Subjects.....	42
	Data Collection.....	43
	Data Management.....	44
	Participant Characteristics.....	44
	Data Analysis.....	47
	Methodological Rigor.....	48
IV.	<b>FINDINGS</b> .....	50
	The Grounded Theory of Protective Care.....	52
	Gaining Control.....	53
	Commitment to Care.....	54
	Preparing to go Home.....	55
	Overwhelming Emotions.....	56
	Organizing Chaos by Establishing Rituals of Care.....	59
	Watching Over.....	63
	Shifting States of Vigilance.....	64
	Developing Expertise and Knowledge.....	67
	Resolving Role Conflict.....	70

Challenging the System.....	71
Advocacy.....	72
Challenging Care.....	74
Controlling Care.....	77
Risk of Alienation.....	78
Promoting Normalcy.....	79
Allowing Flexibility.....	81
Accepting Uncertainty.....	82
Fostering Acceptance.....	82
Normalizing Feeding and Eating Behaviors.....	86
Putting Life in Perspective.....	92
Coping with Lost Personal Opportunities.....	93
Experiencing Anger and Guilt.....	95
Finding Respite.....	99
Establishing Support.....	100
Contemplating the Future.....	101
Celebrating The Positive.....	103
V. DISCUSSION OF FINDINGS.....	107
The Grounded Theory of Protective Care.....	107
Gaining Control.....	108
Watching Over.....	109
Challenging the System.....	110
Promoting Normalcy.....	113

Putting Life in Perspective.....	115
Celebrating the Positive.....	115
VI. IMPLICATIONS AND RECOMMENDATIONS.....	117
Critique of the Study.....	117
Implications and Recommendations.....	118
Health Policy.....	118
Nursing Practice.....	119
Nursing Education.....	121
Research.....	122
Conclusion.....	124
REFERENCES.....	125
APPENDICES .....	141
APPENDIX A	
Summary and Critique of Selected Research.....	142
APPENDIX B	
Recruitment Flyer .....	145
APPENDIX C	
Approval of the Committee on the Protection of Human	
Subjects at the University of San Diego .....	147
APPENDIX D	
Consent Form... ..	149
APPENDIX E	
Interview Guide.....	151

## LIST OF FIGURES

FIGURE		Page
1.	Protective Care: A Theoretical Model of the Experiences Of Mothers Caring for Children Dependent on Parenteral Nutrition.....	51

## LIST OF TABLES

TABLE	Page
1 Characteristics of Participants.....	45

## CHAPTER I

### FOCUS OF THE INQUIRY

Home care of technology-dependent infants and children has become an accepted and expected consequence of higher survival rates among critically ill newborns and children who develop chronic illnesses. Many of the infants are taken home from neonatal intensive care units (NICU's) where as a result of life-saving measures instituted at and immediately after birth, they are rendered technology-dependent for weeks, months, years or for the rest of their life. These NICU "graduates" as they are called, require life-support equipment previously only reserved for hospital care. Older children may also become technology dependent as treatment for an acquired chronic condition because of increasing survival rates of seriously ill children. Some of these children will overcome their dependency on technology and complex care, but many never will.

The conditions which cause this technology dependency in a newborn are often the direct result of aggressive medical management of low birth weight (LBW) and very low birth weight (VLBW) infants. In the United States, 354,964 low birth weight infants were born in 1998 (Guyer et al., 1999). The rate of LBW (<2500 g) infants was 7.6% of all live births in 1998, up from 7.5% of all births in 1997. The percent of VLBW (< 1500 g) infants also rose in 1998. Low birth weight infants and very low birth weight

infants tend to have congenital anomalies and to develop respiratory and digestive system disorders, stemming from complications of the interventions that have been used to prolong their lives (Damato, 1991).

Due to the tremendous cost of prolonged hospitalization for these children and the deleterious effects to the child's development, home care is considered an obvious and viable alternative. Although the infant or child usually goes home to a family, it is the mother who often feels the impact of care (Anderson & Elfert, 1989; Boland & Sims, 1996; Brunier & McKeever, 1993; Katz, Baker, & Osborn, 1991; Kohrman, 1991; Krajewski, 1990; Patterson, 1988; Sims, Boland, & O'Neill, 1992; Turner-Henson, Holaday, & Swan, 1992). She is expected to become knowledgeable about the child's condition, familiar with the intricacies of machinery necessary for life, effectively manage complex care, and provide an environment for this child to grow and develop. The ICU has moved to her living room (Wong, 1991), and her physical, psychological and emotional cost of caring has largely been ignored.

Okun (1995) offers,

The survival rates for critically ill children continue to rise. Our inclination to incorporate increasingly sophisticated technology into our everyday lives seems unlikely to turn around soon. Current market forces greatly support the growth of nursing, equipment, and servicing agencies that provide everything required in the home but the parents themselves. For all these reasons, the use of advanced technology in children's homes is likely to expand.... It is essential that we understand, and not presume we know, the effects of what we do (p. 48).

One of the high-technology modalities, which foster dependence of these infants and children, is parenteral nutrition (PN). Infants, who become dependent on parenteral nutrition soon after birth, have various congenital or acquired conditions, which have



necessitated removal of large portions of their intestines, reducing or eliminating the ability to absorb oral or enteral feedings. The resulting condition is termed "short gut" or short bowel syndrome. Children who develop complications from other gastrointestinal disorders may also require periods of parenteral nutrition to "rest " the gut or may become dependent on PN if the gut is destroyed or removed as a disease consequence. Parenteral nutrition also called total parenteral nutrition (TPN) supplies life-sustaining nutrients through a central venous catheter and requires the use of machinery to pump this fluid directly into the bloodstream (Ament, 1995).

Between 1989 and 1992, the number of home parenteral nutrition (HPN) patients and the dollars spent almost doubled (Howard, Ament, Fleming, Shike & Steiger, 1995). In 1992, there were an estimated 40,000 patients using HPN in the United States. The total dollars spent on HPN were \$780 million in that year. In 1978, 7.4% of all patients receiving HPN were 10 years or younger; in 1988 that number climbed to 13.7%. Only rough estimates of the number of pediatric patients requiring this modality are available, as reliable statistics do not exist due to lack of coordination systems between hospital and community based home-care services to provide tracking data for these children (Cluff & Brennan, 2000).

In 1993, the home infusion industry reported national revenues of \$5.1 billion, and nutrition therapies were estimated to be 25-30% of this revenue. Home nutrition support, particularly via the parenteral route, is one of the most expensive domiciliary therapies. A typical child receiving HPN in 1995 had direct and indirect costs of \$50,000 to \$75,000 a year (Ament, 1995). Although home care in general costs less than inpatient

stays in the hospital (unless the child needs nursing care for close to twenty-four hours a day), it is still a costly program. The principal cost saving comes from the substitution of parental services for that of professional nursing in the home. Most of the money comes from programs funded by state or federal dollars, but the family must absorb the rest. The costs of the substitution of care, lost opportunities for work or to engage in the tasks of living, not to mention the emotional costs have not been quantified (Primeau, 1992).

The impact on the mother who provides highly technical care coupled with the demands of a medically fragile, chronically ill child warrants a closer look. A limited number of studies have examined the effect upon these women's ability to adopt and maintain the mothering role, when required to care for a technology dependent child at home. The effect of the medical community's ability to maintain lives with complicated technology needs to be examined from the perspective of the one who will provide the sustaining care, once the child is deemed "well" enough to go home. "The prevailing attitude seems to be, 'Women are good at this sort of thing; and besides, if they are already at home, surely they can always make room for one more responsibility'" (Arras & Dubler, 1995, p. 8). Realistically, many of these mothers have not been full time mothers, but must give up outside employment, income and personal life goals for a seemingly endless life of care.

The ritual of feeding a child is deeply embedded in the mother-child relationship and an integral, inherent demand of motherhood (Apple, 1987; Devault, 1991; Ruddick, 1995). Additionally, maternal attachment has implicitly been assumed to not only be fostered by feeding, but maternal behaviors during feeding have been used to measure

whether that attachment has taken place. In fact these behaviors have been used to determine the level of appropriate interaction between mother and child (Barnard, 1978; Kang et al., 1995). Feeding in the traditional sense may be absent or radically altered in this population and so may reveal an important perspective of mothering these children.

Numerous mothers feel as if they are on a "solitary journey" and no one "out there" understands or cares about their plight (Aneshensel et al., 1995; Boland & Sims, 1996; Devault, 1991). These subjective experiences are not "being heard or well – represented in the mainstream cultural discourses of psychological development, clinical practice, or social policy" (Coll, Surrey, & Weingarten, 1998, p.xv). An imperative then to examine the experience of mothering a child dependent on parenteral nutrition exists, as an increasing number of low birth weight babies and children are becoming dependent on technology indefinitely to maintain their lives, an undetermined number of these children are sent home dependent specifically on parenteral nutrition, and the experience of these mothers has remained uncovered, undervalued and ignored.

#### Lines of Inquiry

The purpose of this study was to examine the process of mothering a child dependent on parenteral nutrition and to develop a substantive theory based on the perceptions, beliefs and feelings of these mothers. The questions which were addressed include: How do women practice the mothering role while caring for a child dependent on parenteral nutrition, and how do these mothers interpret their role in the lives of these children?

Acquiring this information was accomplished by means of grounded theory methodology. Grounded theory utilizes symbolic interactionism to bring meaning, identity, and experience of everyday life to explain the social world (Blumer, 1969).

#### Theoretical Underpinnings of Methodology

Blumer's (1969) theory of symbolic interactionism as shaped by Glaser and Strauss (1967) and expanded by Strauss and Corbin (1998) for grounded theory research provided the theoretical perspective for the study. Three premises undergird symbolic interactionism. These are: (a) individuals act toward phenomena on the basis of the meanings that these things have for them, (b) individuals develop meanings through social interaction with others, and (c) these meanings are modified through an interpretative process used by the individual in dealing with the things he encounters (Blumer, 1969). "Symbolic interactionism sees meanings as social products, as creations that are formed in and through the defining activities of people as they interact." (Blumer, p. 5)

Glaser and Strauss (1967) based their concept of grounded theory analysis on this foundation of symbolic interactionism to explore the social processes present within human interactions. Glaser and Strauss maintained that theory enables prediction and explanation of human behavior, and provides understanding of situations. Rather than verification, grounded theory strives to generate theory by observation, recording and analyzing.

Charmaz (2000) advocates a constructivist approach, which finds a "middle ground" between postmodernism and post positivism. This method of theory

development encourages the creation of knowledge by both the researcher and participant and is not based on the fact that unbiased data collection occurs or should occur. Rather than strict “formulaic procedures” for data collection, strategies of grounded theory rather concentrate efforts towards the analysis and evaluation of data for “fit work, relevance and modifiability” (p 510-511).

### Significance of the Study

Debate continues over whether interventions should be made to sustain the lives of infants and children who ultimately become dependent on technology. This study provides an insight into the lives of one group of mothers who have been expected to provide the ensuing care necessary for growth and development as a consequence of efforts to sustain the lives of these children. Current studies have begun to examine the impact of caring for these technologically dependent children. Beginning knowledge exists in these areas: (a) the distress of parents related to the infant who is in the intensive care unit, (b) the burden of caring for a child with complex medical needs, and (c) psychosocial stress associated with this intense caregiving and conversely, the positive outcomes which could result from this caregiving experience.

Technology dependent children are essentially hidden from society at large and their mothers are even less recognized. In this country, where aggressive treatment of high-risk infants is routine and the subsequent technology-dependent child is relegated to home care, it is imperative that the mothers who are providing this care be given a voice. The number of these mothers may be relatively small at present, but will continue to climb, and these children will demand never-ending care.

Except for selected specific diagnoses, the preponderance of studies has grouped technology-dependent children together with medically fragile, chronically ill children. No specific study has examined the mothering of an infant or child dependent on parenteral nutrition.

Technology has become a driving force for change and the term 'technological imperative', or the notion that any technology that can be used should be used is an idea discussed and debated from a medical ethical perspective. Baker (1996) offers, "Technologies seem to have evolved faster than our wisdom to manage them...." (p.1). While technological advances cannot be prevented, it is crucial that technologies are examined from the point of view of both good patient care and cost containment (McNeil & Cravalho, 1982; Binstock & Cluff, 2000).

This study has added to the increasing body of literature addressing chronicity of illness in our present day world. Grounding the theory of mothering a child who is technology dependent specifically on parenteral nutrition permits a better understanding of this intense caregiving experience from the perspective of these mothers. This understanding enables nurses to plan, implement, and evaluate strategies for nursing interventions as well as influence social and political policies which affect mothers giving care at home to these children dependent on technology. Improved knowledge about the care rendered by mothers of these medically fragile technology dependent children should lead to developments that might reduce medical costs (Holditch-Davis, Miles, & Belyea, 2000).

Although nurses may not make decisions regarding initial resuscitation of low birth weight babies, they contribute significantly to decisions to continue or discontinue technology by influencing physicians and family (Anspach, 1997). They are also instrumental in discharge planning, case management and care of mothers and their children when they are discharged requiring high technology care including mothers of children dependent on parenteral nutrition. Nurses are instrumental in the assessment and identification of mothers for whom home care is an appropriate and desirable decision, but must also be alert to signs of role strain which may indicate the need for intervention. It is imperative that informed professionals make the decisions surrounding planning, management, and care of these infants and children with the knowledge of the role, mothering these children entails.

The results of this study can lead to exploration of alternatives to home care for technology dependent children. With the uncovering of the effects of sustained care of these children to their mothers, nurses can advocate for the availability of substitutes to home care to provide respite care. This might be provided through extended care facilities, small group homes where care taking is shared, or other forms of care and respite care might be developed through the advocacy of nursing. Through nursing advocacy, social policy can be generated to make these resources available to mothers of technology dependent children.

## CHAPTER II

### CONTEXT OF THE INQUIRY

To provide a background for this study, four bodies of literature were reviewed. First, the development of medical technology and the care of children were explored in general with specific attention to historical aspects of technology and the evolution of home care for the technology dependent child. Second, the technology of nutritional support from the standpoint of the child with short bowel syndrome dependent on total parenteral nutrition was examined. Third, literature related to mothering including social expectations of mothering and the theories of mother-infant attachment and feeding as a mothering behavior were analyzed. Fourth, mothering the chronically ill, and /or medically fragile, technology dependent child was studied. The resulting analysis and critique of this literature provides the background and justification for this study.

#### Medical Technology and the Care of Children

Patel and Rushefsky (1999) have identified seven factors that have fostered the growth of medical technologies. These factors are: (a) an increase in biomedical research and technology as a result of subsidy by federal dollars; (b) increased private sector spending in research and development of medical technologies; (c) the third party payor system has fostered growth of technology, to enhance the quality of care, regardless of the cost; (d) hospitals hope to recruit physicians and attract patients with the latest



technologies; (e) the fascination by physicians of technologies that reduce ambiguity and uncertainty, save time, and confer power; (f) the lack of regulation of the diffusion of technology, and (g) cultural demands for access to technology, faith in scientific progress and expectations of no limits on health care.

Hospitals and physicians have accepted the 'technological imperative', the idea that any technology that can be used should be used (Baker, 1996). Technology in health care in the United States has not only changed health care delivery, but also created expectations among health care providers and consumers (Patel & Rushefsky, 1999). Ethical dilemmas abound concerning the institution and withdrawal of technology, as there are very few mechanisms in place to regulate the development, funding, use and impact of these high-cost interventions (Devetterre, 2000; Feinberg, 1991)

Consequently, developments in life-sustaining technology have resulted in a large population of children who are not only chronically ill but also technology dependent. Technology dependent refers to "children who use a medical technology (embodied in a medical device) that compensates for the loss of normal use of a vital body function, and who require substantial daily skilled nursing care to avert death and further disability" (U.S. Congress, 1987, p. 95). The number of children who are technology dependent is difficult to determine, as most states do not have a method of identifying these children. An Office of Technology Report (1987) estimated that in a given year approximately 100,000 children are technology dependent and receiving care at home. These are conservative estimates from 1987, and no recent figures have been published. However as the numbers of infants who survive low birth weight and very low birth weight climbs,

the incidence of technology dependent children has most certainly subsequently risen. Unfortunately, no tracking system is in place, so as these children are discharged to home care, they become essentially non-existent statistically.

These children are grouped according to the complexity of the equipment, which renders them technology dependent. According to a U.S. Congress report (1987), the groups from the most to the least complex are: (a) Group 1 requires a ventilator; (b) Group 2 requires devices for total parenteral nutrition; (c) Group 3, daily dependence on some other device for respiratory or nutritional support, such as a tracheostomy, oxygen support or tube-feeding; and (d) Group 4, an apnea monitor, dialysis or other devices, such as catheters and colostomy bags. The infants and children who fall into Group 1 through 3 are further defined as needing high technology care.

In summary, technology has been embraced and accepted by hospitals and physicians. However few mechanisms exist to regulate the use of this technology, consequently increasing numbers of children are becoming dependent on technology. These children essentially disappear as no continuous reporting methods exist to provide accountability for their care.

#### Historical Aspects of Technology and the Newborn

Neonatal intensive care units have been cited as an example of “runaway technology” and the invention of the incubator in France in the mid-1880’s set subsequent development of technology in motion (Baker, 1996). Before this invention by Etienne Stephane Tarnier who was inspired by a warming device for chickens, ideal infant care was given by the mother in her home without physician intervention. This

home care included the birth of a premature baby. In the United States as well as Europe, authorities “affirmed that premature infant care was best provided in the home and recommended warmth, nutrition and ‘the unremitting watchfulness and zeal of a devoted nurse or mother’” (Baker, 1996, p. 24).

Tarnier’s successor, Pierre Budin, advocated that instead of the mother caring for these small babies, the infants should be isolated in a room or “special care baby unit” to prevent potential infection (Brimblecome, 1983). Before this innovation, mothers brought premature infants to the hospital up to 2- 3 days after birth, severely compromised, with over 75% of them subsequently dying.

Special baby care units were established in the early 1900’s in the United States. The stimulus for this development was public exhibitions of newly modified incubators by Martin Couney, a pupil of Budin’s in Berlin, London, New York and Chicago. By the 1950’s, intensive care neonatal units became increasingly widespread (Brimblecome, 1983).

During this time, a major attitudinal shift occurred in physicians, who encouraged the physical isolation, and care of these premature infants in special care units. In the early nineteenth century, the premature was often regarded as somewhere between a fetus and a weak newborn. Mothers, although still relying on midwives at home births, would often call in a physician to perform resuscitations of what initially appeared as stillborn infants (Baker, 1996). Physicians, although they might be present at the birth and perform resuscitation, turned over subsequent care to the mother. “Once the infant had breathed, it graduated from the domain of the physician to that of the mother ... the key elements of

such care – warmth, breast milk, and tender nurture – remained shrouded in the mystique of motherhood...." (Baker, 1996, p. 25).

The invention of the incubator, however, began the transition from care by the mother to that of the physician.

The metaphors of the artificial uterus, nurse, and environment symbolized the effort of science to imitate and improve upon nature. In the process, the incubator came to embody a challenge to the traditional notion that the key to raising a weak or premature infant lay in entrusting it to the mother and a healthy home environment (Baker, 1996, p. 85).

Accompanying the invention of the incubator, discovery of a means to intubate infants with tracheostomies, the use of positive pressure for ventilation, and the use of gavage feeding all combined to accelerate the use of technology on a small or premature infant (Brimblecombe, 1983). By 1930, there were a large number of special care baby units in the United States and the neonatal nurse became a "mediator in the transfer of responsibility for the premature infant from mother to doctor. Mothers... lost a certain degree of control" (Baker, 2000, p. 326). Presently medicine has come back to the notion that the mother at home provides the best, most cost efficient care for the premature infant. But not until after the medical interventions and the initiation of dependence on technology does the infant go home, as the child's care is now too time consuming and expensive for the hospital.

In summary, care of the premature infant has historically evolved from an exclusively mother dominated activity to medical intervention in the form of devices to prolong the child's life. These methods have progressed from simple warming devices to

include sophisticated life-sustaining technology. Consequently mothers of these infants are expected to continue the care initiated in the hospital at home.

#### Evolution of High Technology Home Care for Children

Since the institution of home care, the quality of life for the technology dependent child may have improved (Weber, Tracy, & Connors, 1991). But the mother is expected to spend time, effort, and dedication in this challenging and extensive care, to maintain the technical equipment and foster "normal" growth and development of the child, despite multiple setbacks, repeated rehospitalizations and reoperations.

The recent evolution of home care for post-hospital acute care is driven by three major factors. The first and foremost is cost savings. In the 1980's, health care costs escalated to three times the inflation rate because of the expansion of health care coverage with the advent of Medicare (federal) and Medicaid (federal and state) programs begun in the 1960's. As the costs began to rise, third party payers, particularly the government began to ask where the money was going and why (Handy, 1988).

As a result, diagnostic related groupings (DRGs) were developed based in part on the client's diagnosis, usual hospital stay for that diagnosis, and client's age. From these data a standard length of hospital stay was determined. When prospective payment systems began utilizing this information and restricted payment was based on allotted time and treatment, the obvious result was a patient who went home "sicker and quicker" (Malloy & Hartshorn, 1989). A landmark study by Brooten, Kumar, Brown, Finkler, Blakewell-Sachs, Gibbons, & Delivoria-Papadopoulos (1986), determined that it was both cost efficient and developmentally beneficial for low birth weight babies to be

discharged home earlier than they had been. The study showed that sending home a very low birth weight infant 11 days earlier than usual realized potential savings of \$19,000 per infant.

When the U.S. Congress (1987) investigated home care cost versus hospital cost, the following cautionary conclusions were made regarding the apparent cost savings: (a) a primary reason for cost savings is borne by the family and includes the cost of housing, home remodeling necessary for care of the patient, transportation, respite care and much of the nursing care; (b) home care is only less expensive if it speeds recovery and if it minimizes chances of rehospitalization due to infections or other reasons; and (c) less expensive professional nursing care is utilized by most third party payors to keep costs lower than hospitalization.

Hazlett's research (1989) demonstrated 78% savings when comparing hospital versus home care cost in 15 ventilator dependent children. Utility and water bills at home were not included although they were substantially increased. Lynch (1990) reported cost savings of 87% if the ventilator child is taken care of at home, tempered by the fact that if licensed care providers are required, the cost may soon reach that of hospitalization.

Only recently have some questions been raised regarding the issue of costing out the actual hours of care (Ward, 1990). Ward and Brown (1994) studied care-giving time provided by kin of persons with AIDS. Through interviews and questionnaires of 53 persons providing care, where male caregivers predominated, they concluded when care giving was assigned a monetary value, the amount of subsidy supplied by family and

friends was enormous. They suggested this form of caregiver time needs to be counted in overall cost and not considered worthless.

The second major factor in the return to the use of home care, in addition to cost savings, involved the dramatic increase in the numbers of home health agencies as Medicare began to regulate reimbursement mechanisms for home health care. Home health care has become an explosive burgeoning industry. Corporate home health agencies are developing and hospitals are also moving into the home health care business (Speigel, 1991). Following in rapid succession have been a plethora of durable home equipment suppliers, who have developed and sold everything from portable ventilators to devices for dialysis, creating very lucrative businesses. The market for homecare equipment for children was projected to be \$4.2 billion by 1992. Many of these agencies and suppliers pride themselves on creating a "hospital in the home" (Speigel, 1991, p. 57).

Third, the increasing trend to send high technology dependent children home may have resulted from the positive experiences of some parents who opted for home care. As the number of positive experiences grew, the perception of the medical community became progressively convinced that home care provided optimal care for all technology dependent children.

All three of these factors have influenced hospitals to promote home care of technology dependent children. Anderson (1990) contends, "fiscal matters seem to be the major impetus for deinstitutionalization "... with a failure to recognize the complex factors that influence people's management of illness in daily life" (p. 72). The financial

burden for the hospital is taken up by the unpaid work of the mother (Anderson, 1990; Primeau, 1992; Ward, 1990). These fiscal views are beginning to be shared by others (Turner-Henson, Holaday, & Swan, 1992) as the burden of care thrust on the mother is illuminated.

In summary, the recent evolution in home care is driven by cost savings, the exploding home health industry, and positive outcomes for children who are cared for at home. The role of the mother in the home care experience of a technology dependent child has not been illuminated.

#### Technology and Nutritional Support

Infants and children who need devices for total parenteral nutrition, previously classified above in Group II, require high technology care. This type of technology has also been called "halfway technology" (Thomas, 1975, p. 37), designed for "the kinds of things that must be done after the fact, as efforts to compensate for the incapacitating effects of certain diseases whose course one is unable to do much about. It is a technology designed to make up for disease, or to postpone death".

#### *Contributing factor: Short Bowel Syndrome*

Many of the children who require this type of technology are survivors of short gut or short bowel syndrome (SBS). Short bowel syndrome results when less than 100 cm. of small bowel remains due to resection or a congenital anomaly. Reasons for resection of the small bowel include necrotizing enterocolitis, volvulus (turning of the bowel on itself), and trauma. Jejunal or ileal atresia, gastroschisis (a congenital anomaly in which the child is born with the intestines exposed outside the abdominal wall) and



Hirschsprung's disease (absence of ganglia innervation in the bowel) are congenital anomalies which could also lead to short bowel syndrome (Vanderhoof, 1996). Acquired conditions include Crohn's disease and chronic intestinal pseudo-obstruction (a GI disorder of nerve and muscle).

Necrotizing enterocolitis (NEC), the most common cause of short gut has increased in incidence due to the numbers of very low birth weight babies who have been resuscitated at birth. NEC occurs in 12 % of those neonates with birth weights under 1,500 GMS and 90% of the cases occur in premature infants. Necrotizing enterocolitis was not recognized until the 1950's and 1980's (Neu, 1996). It has now emerged as the most common gastrointestinal emergency in neonates affecting 2000 to 4000 newborns in the United States each year. Approximately 1000 of these babies die each year, with the remainder requiring prolonged hospitalization, high medical expenses and technology intervention at home.

The etiology of NEC is poorly understood, but is thought to involve intestinal ischemia, which leads to necrosis of the bowel. Speculation for the causes of ischemia and resultant necrosis includes the immature mucosal barrier and immune response, poor motility, reduced digestive absorptive function and reduced regenerative potential for tissue damage found in the premature infant. Symptoms include abdominal distention and tenderness, pneumatosis intestinalis, occult or frank blood in stools, intestinal gangrene, bowel perforation and shock. Stages progress from 1-3 with stages 2 and 3 reflecting considerable morbidity and mortality (Neu, 1996). The small intestine affected must be surgically removed resulting in a shortened bowel. Clinical manifestations and adaptation

to the shortened bowel depend on the amount of intestine removed as well as whether the resection included the ileocecal valve (Ladd, Rescorla, West, Schere, Engum, & Grosfield, 1998; Jakubik, Colfer, & Grossman, 2000)

### *Total Parenteral Nutrition*

Less than 30 years ago, death was inevitable following small bowel resection because of ensuing protein and calorie malnutrition (Galea, Holliday, Carachi, & Kaplia, 1992). Beginning attempts at parenteral nutrition were reported as early as 1944, but it wasn't until the late 60's that complete nutrition was supplied to an adult patient (Okun, 1995). By 1971, the first pediatric patients were placed on home parenteral nutrition (HPN) (Ament, 1995).

Today, nutritional support for SBS is continued in this form of home total parenteral nutrition (HTPN) through a central intravenous line and lasts for at least three months after the initial resection of bowel in an individual child. As soon as possible, continuous enteral drip feedings are started through a feeding tube. It has been shown that the gut may over time actually grow and adapt so that the child will eventually be able to take oral feedings; however, this might take 2 months to 2 years to occur and for some patients, is unattainable (Ament, 1995).

Complications are many during this time, ranging from overwhelming central line sepsis to cholestasis or interruption of bile flow from prolonged total parenteral nutrition use, leading to severe jaundice and death (Ament, 1995). "The dilemma of SBS is that while TPN has improved prognosis and prolonged survival, liver disease, the main complication of TPN, often becomes the child's chief cause of morbidity and ultimate

mortality” (Jakubik et. al., 2000, p. 117). These children also may develop ‘food phobia’ when and if they are able to take food orally, gagging and choking when food is placed in their mouths. Food acceptance may take weeks and months unless begun in infancy. Other complications include thrombosis of the catheter, air embolism, hypoglycemia from stopping the infusion too rapidly, hyperglycemia, bleeding from separation of the catheter from the intravenous tubing, leaks in the tubing, fluid and electrolyte imbalance, and pump or power failure (Ament, 1995; Bendorf & Lyman, 1993).

In summary, the child who becomes dependent on parenteral nutrition may have developed a disorder termed short bowel syndrome or "short gut". The most common cause for this disorder is necrotizing enterocolitis, seen in small premature infants. Once the diseased bowel is removed, these infants become dependent on intravenous feeding of nutrients to maintain life. Once dependent on this form of nutrition, the child may develop many complications including food phobia and sepsis.

#### Perspectives of Mothering

Mothering has been defined as a "historically and culturally variable relationship in which one individual nurtures and cares for another" (Glenn, 1994). This is but one definition of many that attempt to describe the mothering role and maternal role attainment. The following discussion will address selected perspectives of mothering which in some way relate to the group of mothers selected for this study. The first section relates various generalized social expectations of all mothers including some commonly expressed emotions inherent in the mothering role. The second section addresses the

concept of mother infant attachment and the third section discusses the importance of feeding as a maternal behavior.

*Social Expectations of Mothering*

The word "mother" evokes an image of care and protection. Maternal instinct implies the innate "inner promptings which induce women to care for their offspring" (Whitbeck, 1984 p. 186). Motherhood is considered to be an essential task of women's development (Phoenix & Woollett, 1991), and is linked inextricably with "mothering". Many feminists believe the idea of the 'good' mother has been developed and perpetuated by a patriarchal society to keep the mother in the home as the primary caretaker. Anderson (1989) concurs that being a competent mother "is not linked to some innate process characteristic of women, but an ideological category derived from the social context" (p. 736).

Bassin, Honey, and Kaplan (1994) offer,

The predominant image in white Western society is of the ever-bountiful, ever-giving, self-sacrificing mother... This image resonates with a mother who lovingly anticipates and meets the child's every need. She is substantial and plentiful; she is not destroyed or overwhelmed by the demands of her child. Instead she finds fulfillment and satisfaction in caring for her offspring (p. 2, 3).

This dominant ideology or collective conceptual system by which motherhood is currently viewed "denies them identities and selfhood outside of mothering" (Glenn, 1994). Other authors suggest that this dominant concept of motherhood may be undergoing redefinition in today's society. Thurer (1994) suggests,

The current ideology of good mothering is not only spurious, it is oblivious of a mother's desires, limitations, and context, and when things go wrong, she tends to get blamed.... There is a glaring need to restore to

mother her own presence, to understand that she is a person, not merely an object for her child, to recognize her subjectivity (p. xii).

Ruddick believes that mothers “see children as ‘demanding’ protection, nurturance and training” (1995, p. xi). She asserts that the response in individual mothers is not “foreordained” and a myriad of feelings may be elicited by a child, including infatuation, delight, fascination, pride, shame, guilt, anger, and loss. Rubin (1984) concurs when she states, “ The capacity for guilt is a component of maternal identity” (p. 126).

Mercer (1995) contends that empathy and mothering behavior have a positive correlation, but the concept is sufficiently abstract to make measurement difficult. Empathy, the ability to share the feelings of another person through the awareness of the meaning of those feelings for that person is considered by Rubin (1984) to be an ability which develops over time and as a result of the mother’s own experience, and is not an instinctual capacity.

Care and caring have been identified with not only the mother, but are considered to be an essence of being a woman. Gilligan (1982) asserts a primary difference between men and women is the woman’s capacity and desire to care. Noddings (1984) regards caring to be a personal and moral definition of women. But both authors address limits to this capacity of women to care. “Caring when it is the result of easy obedience to the natural impulse and to the state of engrossment already established, is not burdensome. But when we move beyond the natural circles of caring, we may begin to feel burdened” (Noddings, 1984, p. 52.). Gilligan (1982) also describes boundaries of caring embodied in the feeling of responsibility to oneself versus self-sacrifice.

Another expectation of motherhood is giving. Giving is also seen as a female characteristic, as Miller (1986) reminds us in her writing, "Women frequently confront themselves with questions about giving. 'Am I giving enough? Can I give enough? Why don't I give enough?' They wonder what would happen if they were to stop giving, to even consider not giving" (p. 50).

Giving, self-sacrifice and suffering for the welfare of others has been identified by Rubin (1984) as "moral masochism" and is considered a normal maternal behavior. However, how this is developed and whether or not this is a conscious or learned behavior has not been explored.

Motherhood implies loving, caring, and giving, but conditions may lead the mother of a normal child to become angry and subsequently guilty. Rich (1986) explains.

Love and anger *can* exist concurrently; anger at the conditions of motherhood can be translated into anger at the child, along with the fear that we are not "loving"; anger at all we cannot do for our children in society so inadequate to meet human needs becomes translated into guilt and self-laceration (p. 52).

This anger and subsequent guilt are usually not discussed openly, but "confined to women's' private conversations on playgrounds, doorsteps, or telephones" (Ross, 1995, p. 398). The required twenty-four hour devotion may generate anger, frustration and resentment during care of a 'normal' child which may lead to behavior that is less than "maternal" (Glenn, 1995; Rich, 1986; Thurer, 1994).

Noddings (1984) in her discussion of caring points out, "The risk of guilt is present in all caring, but its likelihood is greater in caring which is sustained over time"

( p. 39). "There exists in all caring situations the risk that the one-caring will be overwhelmed by the responsibilities and duties of the task and that as a result of being burdened, he or she will cease to care for the other..." ( p.12). A pattern could emerge related to the burden of care giving for this technology dependent child: anger, subsequent guilt, loss of caring, and continuing guilt. Although caring may be an innate part of human nature especially for the woman and mother, the burden of care can become overwhelming. "For many people..., care giving is an expression of extreme altruism, where one's own well being is sacrificed for the benefit of another" (Aneshensel et. al., 1995).

To summarize, mothering has been defined as providing care and protection, an essential task of women's development. Care and caring accompanied by giving have been proposed as female characteristics. Anger and guilt, however, may be an outcome of the burden of caring, especially over time for a technologically dependent child.

#### *Mother-Infant Attachment*

Four theoretical frameworks have been used to describe the attachment between mother and child. Ainsworth (1973) and Bowlby (1969) focused on infant to mother attachment while Klaus and Kennell (1978) focused on the attachment from mother to infant. Rubin (1984) describes in her framework of attachment, a developmental process that begins during pregnancy and continues over the months following birth. During this time, the mother forms an affection for and commitment to the child (Mercer, 1995). After birth, the relationship of the mother with the child is reciprocal. Cues from the baby elicit responses in the mother, who then hopes to receive positive reinforcement for her

next action. Barnard (1985) has described this as “waltzing” where the members of the dyad respond to each other with mutuality, while Mercer identifies this as “pleasurable bi-directional interaction” (p. 130). While these definitions characterize attachment, bonding is thought to be characterized through the relationship between the mother and her infant.

Several researchers have explored the concept of bonding of the mother to the infant. Bonding usually implies a unidirectional mother to infant response. Klaus and Kennell (1976) have asserted that separation of the child from its mother in the period immediately following birth could be detrimental to the mother-child relationship. As this research was partially based on observing animal mother-offspring dyads, criticism to the theory has been made (Richards, 1983; Billings, 1995; Watson, 1991). As higher level beings, it is thought we may not be so easily compared to animal dyads, and may be able to overcome an initial separation through use of reasoning ability.

A premature birth or the birth of a low birth weight child will necessitate initial separation of mother from child. Barnett, Leiderman, Grobstein, and Klaus (1970), examined the effects of separation of mothers from their ill newborns and found that deprivation of interaction led to differences in commitment to the infant, self-confidence in the ability to mother the infant, and behavior toward the infant related to infant stimulation, and skilled care taking of the infant.

In addition, when this infant does go home, low birth weight, especially very low birth weight and those with perinatal complication pose problems for the mother-child interaction. Indeed, the mothers of these infants are “initially more active and intrusive in



their behaviors, but may eventually become less responsive to the child” (Patteson & Barnard, 1990, p. 41).

In summary, attachment and bonding theories abound in the literature. Some researchers have found these relationships might be threatened with periods of separation between the mother and her child immediately after birth, while other theorists do not agree with these findings.

#### *Feeding as a Maternal Behavior*

Rubin (1984) declares, “As an object in the transaction between two persons in giving and receiving, food is more than subsistence, nutriments or foodstuffs. Food represents the regard and caring for the receiver” (p. 67). She continues, “ The giving and receiving of food is the primary vehicle of action-interaction (between mother and newborn). Feeding becomes the criterion of self-esteem as mother of this child and of the goodness of fit of this relationship” (p. 136).

Devault (1991) asserts, “ ...the organization of the work of mothering strongly reinforces women’s involvement in feeding work (p. 112). They learn to pay attention to needs of the child which “develops from both loving concern and the very strong societal prescription that mothers are responsible for their child’s well-being” (p. 116). Because feeding is considered to be essential for nutrition as well as an important opportunity for the development of the mother-infant relationship, the interaction between the mother and infant are often examined to determine if attachment has taken place or the process of bonding is occurring (Barnard, 1978; Kang et.al., 1995).

Humphrey (1991) has postulated that when an infant has problems eating, this has implications for the developing relationship between the mother and child. She maintains that “feeding is a major activity that is repeated several times a day, and it offers the infant and caregiver valuable learning experiences as they coordinate actions to meet the infant’s nutritional needs” (p. 31). Feeding and subsequent weight gain of the infant contributes to the mothers’ sense of self-esteem and parental development.

Although, oral feeding is an interactive process imbedded in the mother-child relationship, the social and emotional aspects of eating and being fed have not been thoroughly investigated in children with disabilities. Canadian researchers Spalding and McKeever (1998) completed a qualitative study by interviewing 12 mothers who were caring at home with a child on enteral tube feedings through a gastrostomy. Using a qualitative data analysis process of “meaning units”, five prominent themes emerged. These were: (a) seeking confirmation of the feeding problem, (b) devising extraordinary practices to ensure children’s survival, (c) “giving-in” to the G-tube, (d) experiencing relief and disappointment, and (e) customizing feeding and moving on. The authors came to the conclusion that “feeding had great symbolic significance and mothers clearly blamed themselves and felt blamed by others when problems arose” (p. 241).

Another Canadian study by Thorne, Radford and McCormick (1997) provides a similar view. These researchers interviewed 16 nurses and 7 parents (mothers?) to ascertain their views on the meaning of long-term gastrostomy in a disabled child. Four of the parents were foster parents and while not clearly defined by the researcher, it is assumed they were mothers. These mothers and, interestingly, some of the nurses,

associated nourishment with their role identities. As all of these children at one time took food by mouth, although poorly, the mothers expressed feelings of failure which were internal as well as external (friends, relatives and physicians), when their attempts at feeding the child failed. "Implied and explicit critique of their ability to provide sustenance for their child awakened the monster of guilt..." (p. 96).

In summary, feeding has been recognized as an important maternal behavior, capable of changing the relationship between the mother and child if disrupted. However the implications for mothers of children in whom this process is altered has not been adequately investigated.

### Mothering a Chronically Ill Child

#### *Issues of Caregiving and Family Stress*

'Caregiver' as a term was not seen in the health care literature before the 1960's (Hoffman & Mitchell, 1998). Since then care giving and 'care-giving burden' have been addressed particularly in gerontological literature. Lubkin and Payne (1995) define caregiver from this perspective, "caregiver refers to a host of persons and associated activities, from individuals who help a parent or other relative in any area to those who provide full-time intensive assistance to a frail elderly person" (p.262). 'Care-giving burden' refers to negative feelings perceived by the caretaker resulting from present and potential problems encountered in caring for an individual (Lubkin & Payne, 1995).

Typically the burden stems from stress. Most literature examining the stress of care giving for chronically ill children often refers to parents and parenting, and then qualifies this assumption, by singling the mother out as the primary caregiver. However

other recent literature proposes it is the mother who is the primary care giver, is most familiar with the child's requirements, performs and coordinates most of the care, and bears most of the burden. The entire family unit is affected by the presence of the chronically ill, technology dependent child, but the majority of the increased burden is placed on the mother. The amount of burden sensed by the other members of the family unit has diffused through the mother, who shoulders the responsibility. They receive less of her attention because she cannot take the time or coordinate activities as she used to do (Turner-Henson et.al., 1992). There may be an increased economic burden if the mother needs to give up her job. The income she generated may have provided for activities and material goods, which can no longer be procured.

As the primary caregiver, the mother experiences the stress associated with the constant care giving. Research thus far has examined family stress of chronic illness (Feinberg, 1985; McKeever, 1992; Shannon, 1990; Teague, Fleming, Castle, Kiernan, Lobo, Riggs, & Wolfe, 1993) from certain chronic illness conditions (Betschart, 1987; Wills, 1983) and mothers' role in chronic illness (Miles, D'Auria, Hart, Sedlack, & Watral, 1993). A paucity of research exists regarding the impact of care of a child needing high technology care and nothing, which specifically addresses mothering the child dependent on parenteral nutrition.

In summary, stress of parental caregiving to a chronically ill child has been examined in the literature, but has not always recognized the importance of the mothering role in this ongoing care. The care of a technology dependent child has not always been identified as different from one who is chronically ill or medically fragile.

In addition to the term “chronically ill” and/or “technology dependent”, the term “medically fragile” is also used in the literature. Technology dependence has been described above. The child who is chronically ill or has a chronic condition will experience one or more of these sequelae: (a) limitation of functions appropriate for age and development; (b) disfigurement; (c) dependency on medical technology for functioning; (d) dependency on medication or special diet for normal functioning or control of condition; (e) need for more medical care or related services than usual for the child’s age; and/or (f) special ongoing treatments at home or in school (Jackson, 2000). The medically fragile child has been described as a child who would require hospitalization or institutionalization if home care was not available (Leonard, Brust & Nelson, 1993). The child dependent on HPN may be described as chronically ill, medically fragile or technology dependent, although the medically fragile child is most likely also technology dependent. For the purposes of this proposal, some of the literature examining the care of the chronically ill/medically fragile/technology dependent child at home will be summarized, while literature which specifically addresses the medically fragile, technology dependent child will be explored in greater depth.

#### *Care of the Chronically Ill Child*

Burke, Kauffmann, Costello, Wiskin, and Harrison (1998) completed a meta-analysis of 17 qualitative studies examining the stressors and tasks for families of a chronically ill child. The authors identified 11 stressors and task sets which they labeled “The Burke Framework”. Using this framework, the 11 stress categories are (a) gaining and interpreting knowledge, skills, and experience to manage child’s health problem; (b)

acquiring and managing physical resources and services to manage child's health problem (other than child and health care); (c) acquiring and managing financial resources to care for child's health problem; (d) establishing and maintaining effective social support; (e) rearing a child with a chronic or life-threatening condition; (f) developing beliefs, values, and philosophy of life incorporating child's health problems and the way family copes; (g) management of burden of care for the child; (h) identifying and managing sibling issues; (i) maintaining spousal, parental, and nuclear family relationships; (j) maintaining health of other family members; and (k) maintaining effective relationships with health-care system and other sources of care (pp. 83-87). This meta-analysis adds evidence to their identification of major chronic illness stressors and task sets needed to be accomplished by families caring for the chronically ill.

In other studies, commonly reported experiences in caring for a chronically ill child seem to predominate: loss of identity or self, (Andrews & Neilson, 1988; Skaff & Pearlin, 1992); self-sacrifice, (Anderson & Elfert, 1989); chronic sorrow, (Betschart, 1987; Krajewski, 1990; Phillips, 1993; Warda, 1992); terror or fear (Donar, 1988; Nuttall, 1988; Wills, 1983); anger, (Brunier & McKeever, 1993; Cain et.al., 1980); uncertainty (Cohen, 1995) and guilt (Anderson & Elfert, 1988; Betschart, 1987; Nuttall, 1988; Patterson, 1988).

Levitzky and Cooper (2000) reported explicit aggressive thoughts and fantasies of infanticide in response to a colicky infant. These thoughts were in addition to feelings of depression, anger, anxiety and agitation. Issues of non-compliance, neglect, and refusal to

care for the chronically ill child have been reported by investigators ( Beyers, & Fabian, 1988; Hogue, 1992), but not explored.

In summary, care of the chronically ill child has been studied extensively. Stressors and tasks have been identified relating to the experience of caring for the child who is chronically ill. Studies include reports of emotions experienced, tasks related to managing the illness and the financial impact of the care required. In addition, exploration has been made regarding sources of strength, coping mechanisms and support. A few studies have alluded to the possibility of child neglect and abuse in selected cases.

#### *Home care of the technology dependent child*

A search of the English-language literature using CINAHL and PsycLit data bases from the years 1975 to the present, using keywords, *technology-dependent*, *children* and *mothering* revealed few studies related to technology dependence. There were no specific studies relating to mothering a child dependent on parenteral nutrition. Five studies were selected in which a population of technology dependent children related most specifically to the aspects of caregiving assumed by mothers. Appendix A summarizes the research designs of these studies, their findings and a brief critique. A discussion of these studies follows.

Andrews and Neilson (1988) looked at a six state region in the western mountains to determine the number of technology dependent children living at home and to identify problems with home care. In this geographical area, they found 2,492 technology dependent children at home, ranging from 115 on apnea monitors to 17 on ventilators.

None of the children were dependent on parenteral nutrition. The study was designed to provide a descriptive overview of the types of problems encountered in the care of these children. Data were collected from pediatricians, home health nurses, distributors of medical equipment, pharmacies and mothers of apnea-monitored infants. The problems were classified under the headings of: technical/equipment, family, and financial problems. Technical/ equipment problems were frequent, and many of these families lived in remote areas making accessibility to service more difficult. Family problems this study reported included instances of parental noncompliance in which two mothers deliberately administered less oxygen than medically ordered, thinking they could hasten their child's recovery. In another instance, a mother disconnected the oxygen on a terminally ill child. The researchers also commented on the parents' perceived isolation, which progressed over time as friends and family gave less support. Additionally the study cited loss of self-identity related to interference with careers, employment and interpersonal relationships. Furthermore, families overburdened with care responsibilities along with the uncertainty of prognosis were frequently reported. To cope with financial problems, since reimbursement of costs was commonly at only 80%, parents returned the child to the hospital or in the case of the apnea monitor, returned it sooner than was medically indicated.

Hazlett (1989) in a descriptive study utilizing data collected from chart review, telephone interviews and retrieval of hospital and home care bills examined ventilator management of children at home. Although the author stated this was a family study, the telephone interviews were restricted to the mother. Fifteen mothers who had a child on a



ventilator at home were interviewed. Four of these children received full-time care by registered nurses, five received care eight hours per day, and five received professional nursing care several times a week. Only one patient was exclusively cared for by the mother with no additional professional nursing care.

The study identified maternal concerns including changes in lifestyle due to parental and family activity restrictions, financial burdens, negative sibling behaviors, loss of privacy, and sleeping disruptions. Of the 15 mothers, eight reported physical and/or mental exhaustion. Sources of stress included problems with coordination of supplies, scheduling therapists, and perceptions of incompetence among some of the professional nurses. Contrary to the findings of other studies (Burr et. al., 1983; Frates et. al., 1985) that home care was less stressful than hospitalization, Hazlett (1989) found only five mothers who were of this opinion. The study found that five of the mothers felt forced to accept home care.

McKeever (1992a; 1992b) completed interviews with 25 mothers in Toronto, Canada who were caring for technology dependent children. Based on Ruddick's (1995) maternal concepts, the interviews explored how the mothers: (a) preserved life, (b) fostered the child's physical development, and (c) enhanced social acceptability. Analysis of the interviews used critical theory.

The children varied in age from 6 months to 13 years and all were dependent on some form of technological device ranging from monitors to dialysis. Three children were dependent on parenteral nutrition.

When it came to preserving lives, McKeever found these mothers engaging in complex preservative work as the children were extremely medically fragile. Fearful of changing symptomatology, which might mean the child's condition was worsening, they maintained constant vigilance over the child. They had been previously questioned about their life styles behaviors and habits during their pregnancy on repeated occasions. Many of them felt quite guilty about the child's condition, whether or not they had engaged in an identifiable high-risk activity. Although they felt the necessity of taking the child home dependent on technology, they had been terrified initially, but now had mastered the techniques required. However, caring for this child meant they had to inflict pain while performing routine caregiving on a child many times too young to realize the benefit. They struggled with the expectations of the physician that they as mothers should know and understand the child's condition best, but should still follow the physician's orders without question.

Fostering physical development or providing nurturance proved equally daunting. Many of the children were not normal and feeding remained a source of frustration to the mothers. Speaking specifically about the three children dependent on parenteral nutrition, McKeever (1992), states the abnormality of the feeding situation continued to be bothersome. In addition the feeding became a focal point of their lives, was extremely stressful and carried great symbolic significance.

Enhancing social acceptability posed problems with disciplining a child who was fragile enough to stop breathing when crying. In addition, the physical appearance and enormity of the illness of the child was frightening to friends and relatives, who stopped

visiting. Descriptive comments of these mothers concerning their own health are included under a heading of “overall impact of care giving on women” (p. 189). Only one mother had enjoyed any kind of vacation since her child was diagnosed. None of them had uninterrupted sleep; in fact, 60% of them had had less than five hours of sleep per night for weeks or years. The women suffered from headaches and backaches and worried about their health. Almost all mothers claimed that they were now very aggressive and assertive with health care providers, and many had contacted politicians to lobby for better services for their child. In addition, all mothers stressed positive aspects of caring for this child.

Medically fragile children and their parents were the subjects of another study by Leonard, Brust, and Nelson (1993). Fifty-seven families completed The Brief Symptom Inventory (BSI) designed to measure psychological stress of individuals. Of the participating families, 6 mothers and 42 fathers completed the BSI. The researchers found in 75% of the families, one or both of the parents had a score which indicated a need for psychiatric intervention. These families had been considered ideal candidates for home care.

In another study, Miles, Holditch-Davis, Burchinal and Nelson (1999) surveyed 67 mothers to describe factors predicting maternal adjustment in mothers caring for medically fragile, technology dependent infants. This was a longitudinal quantitative study with data collected at enrollment, hospital discharge, and 6, 12 and 16 months after discharge. The data collected included information on personal characteristics, parental role attainment, infant-illness characteristics, and maternal illness distress. Two-thirds of

the babies were premature and 15 of the 67 had severe gastrointestinal problems, but the type of technology dependence was not identified. The study was based on the premise that distress and growth might be observable in these mothers. The authors used multiple regression procedures and general linear mixed model analysis to arrive at their conclusions. They concluded that while most mothers had experienced personal growth at 12 to 16 months, almost one-half had a risk score for serious depression at discharge and a third still had these scores at 12 months

These five studies represent the research available at the initiation of the study. In these five studies, descriptive self-report questionnaires and interviews seem to dominate the research methods. Four of the five studies addressed their questions solely to the mother, while one, (Leonard, Brust, & Nelson, 1993), investigated perceptions of both parents.

All of the studies limited their participants to small, circumscribed geographic areas or a particular hospital population, which may threaten external validity. Andrews and Nielsen (1988) included a diverse group of participants in their study, including physicians, medical equipment distributors, pharmacies and mothers of infants who were being monitored in an attempt to present a wide view of the population. This only resulted in disparate groups from which it is difficult to draw conclusions about the mothering experience.

#### Critique of the Literature

In summary, researchers have recognized the increasing numbers of chronically ill medically fragile children cared for at home. There is a growing body of literature,

which addresses the experience of mothering the chronically ill, medically fragile child. Many of these researchers have identified the mother as the primary caretaker who expresses the stress and rewards of this responsibility. Additionally, literature exists which supports the concept of maternal attachment and bonding in its relationship to feeding (Rubin, 1984; DeVault, (1991). A few studies have identified a link between maternal anguish and feeding problems ( Humphrey, 1991; Spalding & McKeever, 1998; Thorne, Radford, & McCormick, 1997). However no studies have examined the impact of mothering a child dependent on parenteral nutrition and what that feeding experience or absence of feeding experience means to the mother.

The most obvious gap in the literature is the lack of studies directed to the population proposed in the current study, namely the perceptions of the role of mothering a child dependent on parenteral nutrition. One of many questions, which remain to be answered, includes the mother's perception of that role in light of the limited research on the relationship of mothering and feeding. In addition, a comprehensive theory delineating the mothering process in this technology dependent population has not been suggested. Much of the current research describes pieces of the process, but does not attempt a view of the total experience grounded in the words of the mothers of these technologically dependent children. It is hoped that this research has begun to fill those gaps by proposing a grounded theory of the mothering role with children who are technologically dependent on parenteral nutrition.

## CHAPTER III

### METHODOLOGY

This qualitative study used grounded theory methodology in the framework of symbolic interactionism. This method was chosen as the best “fit” for this study as the experience of mothering and feeding a child dependent on parenteral nutrition has not been examined previously. This method provides the means for elucidating human behaviors and meanings in a social interaction.

This chapter defines the grounded theory method and discusses participant inclusion and entrée to the specific population addressed. Protection of the participants is addressed and the progression of data collection and analysis is described. Finally the methods which provided methodological rigor are explained.

#### Grounded Theory

Qualitative research such as grounded theory is particularly suited to the study of chronic illness because of its focus on meaning and process (Charmaz, 1990; Conrad, 1990; Strauss & Corbin, 1990). Grounded theory usually generates middle range theory through the use of open ended questioning to create and construct through others' perspectives, their own actions and realities. Theory is inductively derived through data collection and analysis (Strauss & Corbin, 1990). Nursing theory traditionally focuses on meaning with an impact on practice (Parker, 2001). Meleis (1997) states, “ Nursing theory is a conceptualization of some aspect of reality (invented or discovered that

pertains to nursing. The conceptualization is articulated for the purpose of describing, explaining, predicting or prescribing nursing care” (p. 12). In this study, a nursing practice theory emerged which serves to address the specific issue of mothering a child dependent on parenteral nutrition. Meleis (1997) has also termed this ‘situation specific theory’.

### Research Strategies

#### *Participant Inclusion Criteria*

For this study, initial purposeful focused sampling was employed to “uncover the situated, contextual, core and subsidiary social processes” (Cutcliffe, 2000, p. 1478), inherent in mothering these children dependent on parenteral nutrition. Mothers were sought who had been caring for a child dependent on parenteral nutrition for at least two months at home and are either still engaged in that responsibility or have done so within the last six months. The initial time frame ensured that the mother had sufficient time to reflect on the experience.

The mothers for this study consisted of two groups. The first group was a convenience sample of mothers who were attending a national support group conference for children and adults dependent on parenteral and enteral nutrition and their families. The second group was comprised of parenterally dependent children and their mothers from a gastrointestinal clinic in a large Midwest children's hospital.

#### *Entree*

The mothers who participated in this study were caring for or had recently cared for a child at home dependent on parental nutrition due to short bowel syndrome or another disorder which has rendered the gut unable to absorb nutrients in sufficient

quantity to sustain life. To recruit the first group of participants, the director, outreach coordinator and local coordinator of a national support organization for families with members dependent on home parenteral and enteral nutrition gave approval for the circulation of a flyer (see Appendix B) seeking mothers at a national meeting. An announcement was also placed in their national newsletter describing the study and soliciting participants. For the second group, a gastrointestinal nutrition nurse practitioner in a large Midwest children's hospital offered to ask mothers for their participation in the study after reading the announcement. She subsequently recruited mothers to participate in the study following the study criteria. The researcher went to the hospital to interview them individually at selected time intervals.

#### *Protection of Participants*

Potential risks to the participants were minimal and indeed as Morse (1988) points out the experience may have been beneficial. Talking has therapeutic benefits, interviews provide a means to ventilate feelings, and validation of worth also comes with the attention afforded by the researcher. Indeed these mothers seemed to welcome the opportunity to express their feelings and many of them wept as they described their mothering experiences.

Anderson and Hatton (2000) suggest that these mothers may have felt exploited in the past by health care providers and might need reassurance that the interview would be non-threatening. Talking about these life events may evoke forgotten feelings in these mothers, which would be potentially painful to relive through interviewing. This researcher was prepared to refer mothers for appropriate counseling if indicated and a list



of potential counselors was given to all mothers who were interviewed at the Midwestern children's hospital.

Following approval of the Committee on the Protection of Human Subjects at the University of San Diego, (see Appendix C), data was collected by the use of in depth interviews with the participants. Prior to interviewing, all participants had the purpose of the study explained to them and were assured of confidentiality. Participants signed a consent form (see Appendix D). Questions were answered and informants were informed of their right to refuse to answer questions or to decide to terminate the interview at any point, if uncomfortable. Each participant received a copy of the signed consent form. Coded numbers provided confidentiality and anonymity of all participants so that no names or other identifying descriptions are present in the data. The list of names with corresponding codes is only known to the researcher.

#### *Data Collection*

Mothers who chose to participate in the study signed a list to inform the researcher of their willingness to participate at the national convention. A convenient time was determined for a face-to-face interview that was conducted in their hotel room for 60 to 90 minutes. One mother was subsequently interviewed in her own home. Mothers who chose to participate in this study from the Midwestern hospital were asked to come to the hospital clinic at appointed times and were interviewed in a private room. The interviews were audio-taped and the researcher recorded observational notes and demographic data.

### *Data Management*

The interviews were completed through open-ended questions, an integral component of grounded theory served to access ideas, thoughts and memories in the words of these mothers rather than the words of the researcher (Reinharz, 1992). "An important challenge in qualitative research interviewing is maintaining enough flexibility to elicit individual stories... while gathering information with enough consistency to allow for comparison between and among subjects" (May, 1991, p. 192). Interviews were guided by a set of open-ended questions. The questions were designed to elicit the meaning of this experience (see Appendix E).

Demographics of the population were identified with each interview. The researcher obtained the age of child, biological or adoptive child, age of mother, educational level, home state, marital status, religion, ages of other siblings, ethnicity, child's medical diagnosis, and length of time on TPN.

These interviews were audio-taped and later were transcribed. Transcribed notes of each interview were kept in a notebook and identified with code numbers. Field notes with other observations recorded at the time of the interview were also kept with the transcribed notes for each participant.

### *Participant Characteristics*

The participants (See Table 1) consisted of 19 mothers ranging in age from 19 years to 54 years. The demographic information of age, religion and educational level was not obtained from one participant. The mean age of the participants was 45 years. All of the women were Caucasian. Fifteen of the 19 mothers were married, two were single and two

**Table 1**

**Characteristics of participants**

<b>Mo.</b>	<b>Age</b>	<b>Marital status</b>	<b>Biological/ Adoptive Child</b>	<b>Education</b>	<b>Religion</b>	<b>Child's age</b>	<b>Child's Diagnosis</b>	<b>Time on TPN</b>	<b>Sib.</b>	<b>State</b>
1	54	Single	Adoptive	MSN	Evangelical Christian	12½ years	Short gut Necrotizing Enterocolitis (NEC)	12½ yrs.	One	NY
2	_____	Married	Biological	_____	_____	14½ years	Short gut Volvulus	14½ yrs.	One	CO
3	51	Divorced	Biological	MSW	Presbyterian	19 years	Short gut NEC	16 yrs.	One	NE
4	38	Married	Biological	MSW	None	11 years	Pseudo intestinal obstruction	9 mo.	One	NY
5	51	Married	Biological	High school	Mennonite	11 years	Hirschsprung Disease	11 yrs.	Seven	PA
6	49	Married	Biological	LPN	Catholic	16½ years	Short gut NEC	16½ yrs.	None	NJ
7	38	Married	Biological	Some college	Baptist	6 years	Eosinophilic Esophagitis	3 yrs.	Three	VA
8	39	Married	Biological	College graduate	Christian	4 years	Short gut Volvulus	4½ yrs.	One	ID
9	34	Married	Biological	Some college	Christian	6 years	Intestinal pseudo obstruction	4 yrs.	Four	CA
10	49	Married	Biological	High School	Christian	16 years	Volvulus	4 yrs.	One	KS
11	19	Married	Biological	Some college	Christian	4 years	NEC Short gut	3 yrs.	None	MO

Table 1 Characteristics of sample  
cont.

<b>Mo.</b>	<b>Age</b>	<b>Marital status</b>	<b>Biological/ Adoptive Child</b>	<b>Education</b>	<b>Religion</b>	<b>Child's age</b>	<b>Child's diagnosis</b>	<b>Time on TPN</b>	<b>Siblings of child</b>	<b>State</b>
12	46	Married	Adoptive	College graduate	Assembly of God	3 years	NEC Short gut	12 mo.	One	KS
13	41	Married	Biological	Some college	Church of God	13 years	Crohn's disease	2 mo.	One	KS
14	43	Married	Adoptive	Technical school	Catholic	11 years	Pseudo Intestinal obstruction	2½ yrs.	One	KS
15	32	Married	Biological	Some college	Methodist	3 years	Reflux- Cyclic vomiting	2 mo.	One	MO
16	41	Divorced	Biological	MEd	Protestant	16 years	Crohn's disease	6 mo.	One	KS
17	47	Married	Biological	Some college	Catholic	18 years	Crohn's disease	4 ½ yrs.	One	MO
18	37	Single	Adoptive	Double Master's	Baptist	2 years	NEC Short gut	18 mo.	Two	MO
19	50	Married	Adoptive	Some college	Nazarene	12 years	Malabsorption	11 yrs.	Two	MO

were divorced. The educational level varied from completing high school to a double Master's degree. Geographically, the mothers live in ten different states representing all regions of the United States. The age of their children dependent on parenteral nutrition ranges from 2 to 19 years with a mean age of 10 years. The number of siblings in the family ranged from 0 - 7. The length of time on parenteral nutrition for each child ranged from 2 months to 16.5 years. Twenty-six percent of these children have been on parenteral nutrition for their entire life and 63% of these children are currently dependent on parenteral nutrition.

#### *Data Analysis*

Data collection and analysis proceed together in grounded theory. This was simultaneously accomplished through the principles of theoretical sampling and constant comparison. As the data were collected through minimally framed open-ended questions, they were 'coded' first through 'open coding', and then focused through 'selective coding'.

Initial open coding was done line by line to help break down, examine, compare, conceptualize and categorize data. Focused coding collapsed data into broader theoretical categories. The 'coding' served to create categories. The coding was constantly compared to other incidents in the same category previously coded. As the coding continued, categories collapsed into broader categories and became fewer. The coding also progressed from substantive codes which utilized the informants words to theoretical codes which began to ask the questions which led to theory formation. Grounded theory studies aim for analytic power and conceptual grasp, which synthesizes, explains, and interprets the data. The rigor of the grounded theory method depends upon developing the

range of relevant conceptual categories, saturating those categories and explaining the data (Charmaz, 1990). Memo writing encouraged exploration of coding already made and let the researcher connect categories and fit them into the larger picture.

### *Methodological Rigor*

Establishing trustworthiness is essential for the grounded theory to be accepted as methodologically sound. Four necessary factors have been identified by Lincoln and Guba (1985) to ensure trustworthiness: credibility, transferability, dependability, and confirmability. According to Krefting (1991), credibility or truth value may be established by spending time with the informants, using reflexive analysis or continual examination of researcher knowledge influence, keeping a field journal, using member checking, peer examination and employing consistent interviewing techniques. All of these techniques were employed in the research methodology.

Transferability or applicability to settings other than mothers with a child with a similar diagnosis is not a specific goal of this research. “Dense background information” (Krefting, 1991, p. 220) to allow others to make suitable comparisons.

A dense description of the research methods and recoding data after time has elapsed can enhance dependability or consistency of the findings. Peer examination of the data and re-questioning of informants can also help to achieve this parameter (Krefting, 1991). Peer debriefing or the discussion of findings with one or more disinterested peers was employed to further establish trustworthiness as described by Lincoln and Guba (1985).

Confirmability was established by leaving an audit trail. This was accomplished by detailed recording of all research activities until the culmination of the study. An attempt was made to record the thought process, which led to the conclusions of the researcher through the extensive use of memoing. The use of reflective analysis and theoretical perspectives were employed to establish confirmability or neutrality as described by Sandelowski (1986). This element serves to root the findings in the informants' responses or data collected rather than the researcher's bias.

## CHAPTER IV

### FINDINGS

This chapter presents the grounded theory which emerged subsequent to the analyzing of interviews obtained from the 19 mothers who participated in this study. The emerging substantive theory for this study centers on mothering a child dependent on parenteral nutrition. After careful questioning of these mothers and analysis of their responses, "Protective Care" emerged as a fit descriptor of the mothering process for these children. Protective Care is embodied in the fierce protective stance these mothers assume in the care of these children who depend on intravenous nutrition to sustain their lives. This care can be best described in the categories of (a) gaining control, (b) watching over, (c) challenging the system, (d) promoting normalcy, (e) putting life in perspective, and (f) celebrating the positive. The diagram (see Figure 1) illustrates the categories and their relationship to Protective Care. Although the categories intermesh in life, for theory purposes they have been delineated and categorized. Each of these categories serves to explain the strategies, consequences and interactions inherent in the process of mothering a child dependent on parenteral nutrition. These categories will be described generally and then examined more closely looking at the sub-categories in each in order to formulate a coherent theory.





### The Grounded Theory of Protective Care

Gaining Control became the antecedent to all subsequent action in the process of protective care. No matter when the dependence on parenteral nutrition began in each child's life, these mothers were eager to get them to a home environment where they could then begin to gain control of the child's care in a more familiar setting. In order to gain control, each mother committed herself to care for this child, learn the care required, overcome fear and feelings of being overwhelmed and isolation, and organize the chaos by establishing rituals of care. Once control was gained, they could begin the work of watching over this child.

Watching Over is characterized by the degrees of vigilance these mothers employed to ensure the protection of these children who need constant monitoring to keep them from disastrous consequences. While employing vigilance, each mother sought role clarity as she developed expertise and knowledge in the care. Watching Over paved the way

Challenging the System in a more confident role, they advocated for their child, controlled the care and confronted the medical and nursing health care providers, reimbursement systems and the schools when necessary. An accompanying strategy, these mother employed as they gained confidence in their role was promoting normalcy.

Promoting Normalcy became a strategy to provide protective care as well as a consequence of their accumulated knowledge and experience. This allowed them to become flexible in their care, accept uncertainty as they encouraged development, fostered acceptance and attempted to normalize this child's feeding and eating behavior.

In order to accomplish these tasks of mothering this child, these mothers needed to be able to put life in perspective.

These mothers devised ways of Putting Life into Perspective, fighting to overcome the emotions that might overcome them by seeking respite, and establishing support in order to maintain the level and intensity of care these children demanded. Here they also contemplated the future, recognizing possibilities of mortality, but maintaining hope. The consequence of the protective care became their ability to celebrate the positive aspects mothering this child had provided.

Finally, Celebrating the Positive characterized discovering the 'silver lining' where they uncovered the sometimes hidden benefits of the intense care given. Here they also celebrated the pride and satisfaction they felt as they successfully mothered these children.

The following sections will use the words of these mothers to depict this integrated theory explicating the trajectory of this protective care. This experience begins with Gaining Control.

### *Gaining Control*

Gaining Control describes the process these mothers took to prepare to take on the intense care each child dependent on parenteral nutrition requires. This category is comprised of four subcategories, which explain this process. The mothers became committed to caring for their child. They prepared to go home, learning the care required in order to take the child home. Once the child was in the home and the mothers could establish their own routines, they began to feel more in control. They overcame fear and

feelings of being overwhelmed and isolated, organized the chaos, and established rituals of care.

### *Commitment to Care*

Commitment to care initiated this intense care trajectory and began when the child became dependent on TPN either shortly after the birth of the child or later in life. For some of these children, dependence came as a result of complications or defects diagnosed at birth and before the baby was discharged home for the first time. For others, the dependence on parenteral nutrition came after many months or years of struggling to feed this child without a definitive diagnosis. For these mothers, the diagnosis and subsequent dependence on parenteral nutrition were somewhat of a relief. Now there was a means to keep the child alive after what may have been a long process in trying to convince physicians something was not right with this child's intake of food. For still others, the dependence on parenteral nutrition was an unexpected consequence of illness in what had been a healthy child. In all of these situations, these mothers (biological and adoptive) made a commitment to care for the child and subsequently gained control of the situation.

The commitment became an expected outcome of the child's condition and was an implicit understanding of the mothering role for the natural mothers and a conscious decision for the adoptive mothers. Speaking of the commitment to care for her child, one mother expressed her reasoning this way, "I don't think there was any doubt or anything. It was more... you cared, you do what you have to do." Another mother stated, "If you love someone enough you'll do anything. It's just a part of love." Still another mother

characterized this commitment as an implicit task of motherhood as she stated, "Well, he's my child and mom provides the care. I took it on when I had him. It's all my job and whatever he needs from me, that's what I'm going to give."

For the adoptive mothers, the commitment came as the result of the attachment they formed with the child evolving from a foster parent relationship first and progressing to adoption. Once they committed to the care, they prepared to take the child home.

#### *Preparing to go home*

A natural reaction to committing to care came the desire to learn the care required for this child's dependence on parenteral nutrition in order to get them home from the hospital. The mothers whose children were coming home for the first time as infants usually spent long hours, days or weeks in the hospital waiting for the child to be stable enough to go home and learning the complicated care involved.

This mother observed:

And we spent 7 months I think in the NICU and I was ready to bring her home. And I think they knew that. They did all the preparations. You sleep in the hospital, you kept the babies in the room, and they totally wait until you're comfortable to take them home. And I was ready.

Another mother stated:

I would do anything and learn anything [to get him home]. That was my mindset. [Before he went home] I was at the hospital every day 18 hours a day, went home to sleep after the first month. I was there before that 24hours/day. I learned his care very quickly.

This mother remarked, "I just wanted to get her out of there [the hospital]. I thought, I have to get my kid out of there." One mother did state that she was never asked if she was

ready: "I don't remember if anyone asked...I don't think anyone came right out and said, 'Are you ready to do this?'... We were just glad to go home."

Nevertheless there were some mothers despite their eagerness to go home with the child, who in retrospect felt shortchanged when it came to preparation and teaching before discharge.

Yes (they taught me before I came home). And I passed with flying colors; I knew how to do all that stuff as a nurse; what to watch for, how to clean it (the site), and when to call, but... maybe she should have taught me more. You know did she shortchange me on stuff I really need to know and watch for?

Another mother had this to say:

Well the hospital kept feeling that we were ready. The home care [nurse] said, 'oh you're fine.' But they weren't answering my questions; they weren't giving me the things that I thought I needed. I requested specifically a wall chart that I could hang on the wall that gave me each step so that it would be easy for me to refer to. I was there when they gave the training in the hospital but my husband wasn't. So I was having to train my husband at the same time I was trying to remember everything myself. And I didn't think that was appropriate.

Another mother states, they "fell through the cracks":

We fell through the cracks. There was a regular TPN nurse [who] was supposed to come to the teachings; she was busy, so we had somebody else fill in. She was in for about 10 minutes briefly going over things in a very general way. And said, "if you have any questions call." We figured it [how to do line dressing changes] out on our own. After he was on TPN for 3 years, they actually gave us a training manual that we supposed to have when we first went home.

### *Overwhelming emotions*

Whether the mothers felt they were ready to go home with their child, or had been taught adequately before discharge, these mothers expressed a variation of emotions once they arrived home. These emotions ranged from being overwhelmed and fearful, to

experiencing denial and feeling isolated when they actually arrived home and began the care themselves. The amount and intensity of care was overwhelming. One mother stated, "It was the most awesomely difficult thing, even now here I am, it's 16 years later and I'm choked up thinking about it." And another said,

I think if I could have gotten by with it, I'd have someone else do it the whole time. I was never so overwhelmed in my life ... and I thought I could handle just about anything. Maybe it would be easier for another mother. Maybe I'm flighty; maybe I'm panicky; or maybe I make a mountain out of a molehill. Or maybe TPN *wasn't* that bad; I don't know. But to me it was overwhelming.

Another mother stated, "[The care was] overwhelming. Confusing... I don't remember which goes together where. It was very stressful. And I wasn't sure I could do it."

This mother observed:

At first it was overwhelming... And you're afraid that you're going to do something that harms your child... So the scariest thing was that if he would get an infection and it would be my fault. So that was just overwhelming.

So in addition to being overwhelmed, fear played a factor in their initial reactions. These mothers expressed some variation of the fear theme as these statements attest:

"Scary, I never had a panic attack before. I came really close. Just very scary to me."

"Very, very scary."

"Frightening...it was frightening."

"It was scary."

"Scared the daylights out of us... it was a very scary situation."

"I knew the catheter went to the heart and all of that. I was always scared that if I press a wrong button, am I going to kill her?"

Fear, particularly of the central intravenous line providing the nutrition was uppermost in their minds. Fear that the line would become infected along with fear that the line might become dislodged or that they might introduce air into the line were common causes of apprehension. Even if they felt that the teaching might have been inadequate prior to discharge, most mothers came away from the hospital setting with great anxiety about losing the central line. If nothing else had been conveyed to them, they had been taught that lapses in care could precipitate an infection of the line or result in death for the child. As a result, many mothers initially expressed intimidation of the technical care associated with the line.

A natural reaction to the fear at least initially was some form of denial. Feelings of denial were common. One mother who wanted to deny her child's condition, after attending a support group meeting described her feelings this way:

I did attend one reflux group meeting... I attended one meeting. And I got so depressed after attending it, I didn't go back. Because these mothers felt the same way I did, and I wanted them to say oh, no, we don't feel that way; it's okay. I wanted... I really wanted it to be me [who] was crazy. I didn't want this to be how it's really supposed to be with a child like this. Because that was depressing. I felt like then, there is no hope. There is nothing that I can do to fix this. I can't fix myself because this is the way it is. And that was very depressing; I just wouldn't go back. And to see these mothers with 2 and 3 years old that... at the time (my daughter) was just maybe 6 months old, and to see that they were struggling with 2 and 3 year olds, and I just... I didn't want that to be me. I didn't want that to be my life, but unfortunately it was much worse.

The volume of supplies required for this child's care created feelings of disorganization and chaos. "I had boxes lined up in my family room and Baggies... one bag was saline, one bag was syringes, one bag was this. It was a total mess." Some



mothers handled this confusion and chaos with denial; "I just wanted to put away all the stuff so I couldn't see it. So I piled it in the closet."

Isolation compounded all of these feelings by giving some moms the impression there they were alone in this endeavor. Some mothers were unaware of anyone else who was performing this same care, " I didn't know anyone else. I honestly thought we were the only ones in the world with a kid on TPN at home and we felt completely isolated." Another mother stated, "We were thrown into the middle of the ocean and left to sink or swim." For the most part though, each mother found a way to tackle the care the first time, because as one mother put it, "I just had to; you have to keep them alive."

#### *Organizing chaos by establishing rituals of care*

For most mothers a necessity to controlling the chaos and beginning to gain control of the situation was organization. Perhaps not immediately, but fairly quickly they developed an organizational plan to make the care more expedient. This mother described her system for organizing the equipment this way:

We have a much better system now; much better. I take them (IV equipment and supplies) out for a whole week; make a pile of each thing; put them in a bag that's labeled for the day of the week; put them in a cabinet and all you have to do is grab a bag. It's got the whole day's supplies in it. Your syringes, your alcohol, part to your machine and your tubing that you need. Every several days I put in saline and Heparin because I know we're going out that day, and the day that we change the adapter, that's in that bag. It's so much easier; it saves so much time doing that way.

Organization served to bring control into her life. A further way to establish control was to construct rituals of care.

Establishing a routine was one way to control the overwhelming, complicated care needed by each child. Each mother had an established pattern of care. Some mothers had the help of a home health nurse in this process, but most did not or realized quickly, that even despite their own perceived incompetence, they knew more about the equipment and care required than the home health care nurses sent to help them. This mother stated: "We had the visiting nurse come one time when she first came home. But they didn't know anything about it anyway. I mean, I knew much more than they did."

When mothers were asked to describe a typical 24-hour period for caring for a child on parenteral nutrition, a composite of the care emerged. Most of these children were "hooked" up to a pump which pushed the parenteral nutrition (PN) fluid through their central line during the night. One bag containing a vitamin enriched fluid and most often, another bag with lipids would infuse through a Y-connector into the central intravenous line. In the morning, the mother would go in and unhook the child from the pump and flush the line with one syringe-full each of saline and heparin to clear the line ensuring it would not clot off while fluid was not infusing. These syringes were drawn up ahead of time using sterile technique and usually kept in labeled containers near the child's pump.

Many children in addition to the central IV line feeding were also on another pump during the night delivering a formula mixture through enteral tubing that went directly to their stomach or small bowel. The ultimate goal would be to eventually progress to either enteral or oral feedings. Some children are on extra medications, which must be infused through the line after the PN is unhooked. Some children are on

continuous PN and only have a window of about 3-4 hours when they are not connected to the pump. Most children who have had bowel removed and are not on enteral feeds, will have an ileostomy or colostomy bag, which needs to be emptied frequently, and the bag changed periodically. If they do not have a bag, they are almost always having constant stooling and if not toilet trained, require numerous diaper changes, baths and skin care.

A mother explains:

Starting in the morning, when he wakes up, we have to unhook the TPN because he's only on that at night. We unhook the feeding tube ... because he's on boluses. [When] he's not on continuous feedings we do boluses during the night but the pump can do that. We unhook that; give him his meds. Unhook the oxygen, because he is on oxygen at night and when he takes naps. And then we do feedings three times during the day. He only gets meds twice a day, when he wakes up and then at bedtime, which is very helpful. Because of the short gut, he has a lot of diapers, a lot of stooling. So we have to deal with that.

In the evening, before bedtime is perhaps when the most intensive care is needed.

Many mothers described a feeling of exhaustion from the whole day of caring, only to be faced with the care required to hook them back up to the PN. The solution to be infused is kept refrigerated. Hours before it's use, it needs to be removed from the refrigerator to warm up to room temperature. Before being infused into the child's central line, specific drugs and vitamins are added to the bag of solution with a syringe using sterile technique. The line itself must be primed and flushed before the infusion begins. During all of these steps, the risk of introducing bacteria into the child's bloodstream is high. The mothers are most often taught measures to reduce the risk of infection including methods of cleaning the catheter tip and sterile dressing techniques for the area surrounding the

insertion point of the central line. This meticulous care required at a time of the day when most mothers were exhausted is described by this mother, "You had to have that reserve... after you cooked dinner and cleaned up... to do really what I considered the most intensive work." Hooking up the child to the TPN, accompanied by dressing changes of the central line consumed the most time and proved the most difficult tasks. Initially these procedures could take as long as three hours each evening, but with experience that time was shortened immensely

The intravenous tubing is threaded through a pump, which must be set with specific parameters so that the proper amount of fluid flows through each hour. The tubing must be positioned so that if this is a baby or toddler receiving the infusion, the line does not become dislodged during the night. Alarms on the pump signal malfunction or line obstruction. During the night many of these mothers set alarms of their own to empty the ileostomy bag, encourage the child to void. As one mother said:

I wake him up usually in the middle of the night to pee because he gets 2 ½ liters of fluid.... so I wake him up and he pees in the urinal.

They may also need to change diapers or the entire bed (because of the fluids infusing all night, the child may be incontinent), or to infuse needed medications. Often, of course the pumps will alarm if not set properly or if the line has been obstructed, requiring the mother to get up to investigate or troubleshoot.

One mother described the care of her 6-year-old this way:

By evening time, I've already gotten a new bag ready, TPN and every thing, and have spent – it's about probably half an hour or so mixing up bags, and getting the tubings like... getting everything set up for the night time. Through the day we have to monitor him for fluids - make sure that he's not needing extra fluids because he dehydrates very fast - especially

in the heat. By evening time, usually around 9 sometimes 10 o'clock or so, we ... he gets his evening meds and then we hook him up, start the whole process again. He ends up having 3 pumps running and a drain bag hooked up and then his enteral pump going through the night. Plus his enteral and then you have the G tube hooked up for drainage. Getting up to take him to the bathroom most of the time through the night, changing his diapers. Sometimes he'll stool during the night, sometimes he won't. It just depends on his stomach. When he feeds sometimes his stomach gets irritated and so he'll have watery stools that have to be changed then, right then. And if he has a good night, we're not woken up very much. When we get up in the morning, we feel pretty good. If he has a bad night, it's not pretty.

Both of these mothers have husbands who also help with the care, hence the use of "we" in the narrative. Support with the required care by the spouse is common, but not universal and despite help, the responsibility for the care and the coordination of the care falls to the mother. The intricacy of the care involved and the fragile nature of each child's condition forced these mothers into a vigilant protective stance.

In summary, this first category sets the stage and begins the protective care, which each mother will continue throughout this child's care trajectory. She realizes that she must gain control over the situation by committing to care for this child, prepare to take the child home by learning the care involved, overcome feelings of being overwhelmed, fear, denial and isolation to organize the chaos and establish rituals of care. The stage is now set for continuing the intense protective care.

### *Watching Over*

"Watching over" encompasses the intense care these children need to survive and the protective role their mothers assume as they care for this child. This care can be described in shifting states of vigilance, which through experience may be adjusted to suit the situation. The vigilant watching over contributed to their growing knowledge

experience base, which served to increase their understanding of the child's condition and served as an antecedent to the subsequent categories. Seeking role clarity became a consequence of undertaking the intense care required. The shifting states of vigilance are described first.

### *Shifting States of Vigilance*

Like all mothers, these mothers kept watch over their children to some degree at all times while in their care. However when undertaking the initial care of these children before a knowledge experience base was formed, the vigilance level might be termed hypervigilance. As the mother gained experience and knowledge of the intricacies and patterns of her child's condition and care, she might move to a more relaxed vigilance. However some of these mothers never seemed to relax their vigilant stance.

*Hypervigilance.* As a result of the intense care needed and the fragile nature of the line on which the child's life depends, these mothers became hypervigilant. They constantly watched over this child, remaining ready to intervene if trouble was sensed, day and night.

This mother describes her hypervigilance:

I mean I'm up every hour; I'm still up every hour making sure her little chest is going up and down, and the pump's still moving. "I just want to make sure that she's still there"... I'm always waking up; my husband is always saying, 'Where are you, what are you doing, why are you out of bed?' Yeah, I check on her a lot. But I'm still up checking on her. She's still there, and I'm still up checking on her. I just want to make sure that she's still there. And we came so close to losing her in the end that I just am really, really worried about her. Now sometimes if I'm really, really tired I'll sleep a couple of hours. But if she perhaps gets sick in the middle of the night, she usually spikes a fever first; a really high one. Usually around 103/104, then something wakes me. And I go

in there and I check on her. But, yeah, I'm always waking up; my husband is always saying, 'Where are you? What are you doing? Why are you out of bed?' I'm just checking; just want to make sure she's breathing. Sometimes her pumps ring off. Like TPN will only ring off for so long, and then it stops. You know, within a very short period of time, when we first started, we had different pumps. They would only ring off for a short period of time. And then I'd miss it. And that's why... we'd tried getting monitors in there and things like that, so I eventually would have to keep checking. I was checking on the pump too. I was running in there and checking on the pump all the time. No, she has never really pulled out a line or... occasionally sometimes her NG tube will come disconnected and milk will leak, but I usually catch it in the middle of the night.

Most mothers start out with this sense of hypervigilance, but if they did not, there is usually some event which jolts them into becoming hypervigilant. For some mothers this means having the child sleep in the same room, so the pump alarms can be heard; for others, it means sleeping with "one eye open", and for others it means performing extra care with the central line, swabbing ports more often than they had been taught, to avoid infection. This mother describes what happened when her child was not initially in the same room with her:

The first year or so on TPN, he was not in our room, and we lost ... a couple lines, because we couldn't hear the pumps alarming. And he didn't know the difference. And it's ... things happen... we've had him wake up in the middle of the night where the tubing has broken. At one point we were using these Y extensions. But we don't use them any more, because they broke way too many times. But they break and he'd wake us up in the middle of the night saying, 'mom I have blood all over me, I think my line broke.' You know, sure enough, we turn on the light, and he's got blood all over his shirt. So we need to be able to hear him. He wakes up not feeling good, or if he starts thrashing around, I know something is going on. He's not... he's got a headache, he's running a fever, or his stomach is hurting or something. So neither one of us is completely comfortable with him in a different room, because the rooms are pretty far apart also. Even with the monitor on at night, would I be able to hear him well enough.

*Relaxed Vigilance.* As these mothers became more proficient in the care and the child became somewhat stable, the vigilance might be relaxed, especially if the mother wanted to create a more normal environment for herself or her child as this mother explains:

You cannot live at that height of emotion where you fret about every little thing, or he won't be normal; my life won't be normal; it won't work.

Another mother explains how their level of vigilance changed as time went on:

The first few times, when he was on it the first time, with the PICC line and six months later when they put him on the Hickman. Because he was younger... he was like 13. And he would... we would hear it go off. And we immediately fly out of bed. Or if we didn't hear it, he'd come in our room, and say the alarm is going off and I don't know what's wrong, or something. And we'd investigate what the problem was. Rectify it; fix it, or whatever. And then he'd go back to bed and we'd go back to bed. I think each time... when he would first go back on it, there would be a few sleepless nights, because you didn't know... make sure everything was going okay. And did we get all the air out of the line...you know... all the stuff you worry about. Cause he was worried about the air in the lines. And then one of the nurses one time when he was in the hospital said, 'Oh those little 7-up bubbles aren't going to bother you. It's the big ones; the little ones you'll be okay.' And I think as he got older, he realized they weren't going to hurt him. So he'd relax and so we'd relax.

However for some mothers certain facets of vigilance were never relaxed especially if doing so carried the risk of compromising the central line as these mothers point out:

"And when you know there's only so many sites for that port, you get real protective of those sites."

"You had to really be conscientious, you couldn't be sloppy with it...you can't be sloppy."

"We still use a lot of the old methods that we were originally taught. Because if it works don't change it. And so we use sterile Q-tips and alcohol and Betadine."



“But I always felt like well, he’s not going to get an infection because of what we’ve done at home. I mean that just wasn’t okay.”

Many of these children had parameters of their care which always required a need to be watched over: fluid balance, signs of sepsis, and meticulous care of the line and its insertion site. The progression of vigilance is perhaps best described by this mother who states:

My main theme or saying used to be 'one day at a time, and if the day is too long, then one hour at a time' because that is about the way it was. It can change so quickly, but it is more stable now. It’s not quite as day-to-day change like it used to, and hour to hour change. But it’s still a week to week change.

As the child's condition stabilized, the vigilance could be relaxed and as the result of developing expertise about each child, a better understanding of the aspects of the child's care which needed continued vigilance emerged.

#### *Developing Expertise and Knowledge*

The second theme of the Watching Over category is developing expertise and knowledge. Mastering the complicated care of this child might be accomplished in a short period of time. This mastery could be accomplished if no complications arose, if the child was not progressing through developmental stages or if the care stayed the same. This is however rarely the case once a child becomes dependent on parenteral nutrition. More often, it might well be a year before the mother considered herself an expert. Most often in that first year of parenteral nutrition, the central line became infected numerous times, or the child developed other complications, which required frequent long-term hospitalizations. There appeared to be a learning curve for the mother as well as the physician. One mother described that first year this way:

She came home like three months after her birth; when she was born. And then bounced back and forth [to the hospital] the first year. They weren't managing her fluids too well and stuff. And your instinct kicks in and you start [realizing how to balance fluids and prevent infections]. And then she became pretty stable as it went on.

Other mothers describe frequent long hospital stays the first year, hospital stays of up to 8 to 9 weeks, totaling 8-9 months of hospitalization in the first year. The development of expertise and knowledge came from intuition, experience and outside sources. The intuition that each mother develops is explained well by this mother:

...There is an intuitive feeling that you feel about this and you're right. I don't care what any doctors, nurses or anybody else says. You know that person. And it's really important to pick up on that.

The knowledge base was not only accumulated from experience, but from people the mother sought out for advice through formal and informal means, as this mother states:

And I've learned from other parents and other parents have come to me. I've asked that question around and I've been watching it over the last three years.

Obviously much of the knowledge they accrued came directly from the health care team who managed their child's care, as this mother asserts:

I didn't realize at the time, we could group some of her meds together rather than giving meds at 8, 9, 10, 11, and 12. I didn't know you could do all this. We actually worked into a system, where we're just giving her meds 4 times a day, instead of every hour. But we have to draw meds; I didn't realize you could draw them up 2 days at a time, put them in the refrigerator.

However, other knowledge could come from support groups, through the Internet or from other selected sources. Often the knowledge and or advice was conflicting forcing

these mothers to make their own decisions regarding the care of the child, as this mother points out.

[When physicians disagree] I don't know if I'm making the right decisions and I don't know if I should be doing something differently. I have to base my decisions on which one of you I think is right today. And whether I make the right decision or not, could have a significant impact on the outcome - life or death.

This mother explains how she needed to know a bit about all the specialties to make her own decisions:

The medical profession does not come with guarantees and I learned a lot about it all and I kind of feel like I have to like to renal team stuff and the GI team stuff, and the endocrine people's stuff, and the orthopedic docs stuff, and I have to process through it all and come up with the reasonable [solutions].

The knowledge gained from experience resulted from these mothers learning what works or what to expect when a specific event occurs so they can prepare for it as these mothers explain:

“And sometimes he eats because he thinks he's hungry, but he's really thirsty. I figured it out.”

We have an urostomy bag (on her jejunostomy) because her stool is so watery; it's more like urine. And I was getting up all night draining this bag, so we improvised something. I get these bedside drain bags and I cut the tubing off, we don't use the bag for it. And I attach the tubing to her urostomy bag and hook that into a pail, like a Rubbermaid pail. That way I don't have to drain her bag at night.

If he needs antibiotics for whatever reason, that throws everything out of kilter; not only do you have to schedule to do the antibiotics, but we always know Zofran is coming, he'll need antibiotics. Diarrhea is coming; we're going to have problems with skin integrity; all these things are going to happen. every time you give antibiotics which is very common.

While these mothers are learning and caring, they often become aware of a duality of roles which might be approached in different ways depending on each mother's philosophy of care. This was identified as resolving role conflict.

### *Resolving role conflict*

For some of these mothers, because of the intense care they give, a conflict arose between what they would describe as the mothering vs. nursing role they play in this child's life. Two approaches to this conflict were identified, separating the roles or integrating the roles.

Separating the roles assumed the existence of two distinct roles. These mothers needed to disengage from one role to perform the other effectively. Mothers spoke of stepping out of the mothering role to perform painful but necessary procedures. It was as if they remained in the mothering role, they would not be able to tolerate the anguish expressed by their child. This mother expressed that dichotomy best when she stated:

I just try and put the mothering thing aside when I'm having to do even painful things ... I just have to put myself aside and forget I'm the mom and then do what I have to do. I just kind of have to forget being the mom while I'm in the process of doing something medically for her. And then after it's over then I can be the consoling, comforting mother.

The 'mom' role also disappeared when they wanted to relate to health professionals as some mothers thought that approaching a problem from a 'mom' point of view wouldn't give them much credence and definitely would not allow them to dialogue on the same level. This mother expressed those opinions the best:

When I bring her here to clinic and we come here exclusively... I can't be just mom. I have to be able to relate to our professionals on their level. If I want to get a ... not necessarily a positive response but that they understand what I'm telling them. And at the beginning, I think I

probably was a hysterical mom, that 'oh, god there's air in tubing what am I supposed to do?

Another mother begrudged the fatigue she felt from the 'non-mom things', by saying, " I don't mind being tired from 'mom' things but it gets old being tired from doing non-mom things."

However other mothers felt the roles were integrated and could not be separated out. The roles could also be performed simultaneously. This mother offered:

I think in some aspects they're one (mom and nurse) and the same. Because when you look at what's a mother and what's a nurse. You're basically... with the exception of the love, which I'm sure a lot of nurses love their patients... But there are certain aspects of it that are exactly the same, and then there are certain aspects of the two jobs that are a little different. But I think they kind of... if you're a mother, you've got a little bit of nurse in you and if you're a nurse, you've got a little bit of mother in you.

In summary, *Watching Over* encompasses the states of vigilance related to the intense care needed for each child. This is accompanied by a developing expertise of care perfected over time. During this intense care a role conflict between mothering and nursing may emerge and is resolved either with a dichotomy between roles or a blended role. Armed with expertise and knowledge, these mothers are now equipped to take on other challenges within the system.

### *Challenging the System*

Challenging the system refers to the ability and methods these mothers demonstrate when necessary to advocate for their child with the health care system, reimbursement care issues and the schools. Additionally it includes challenging and

controlling the care of the child, which carries with it the risk of alienation. The first subcategory is advocacy for this child.

### *Advocacy*

Advocacy for the child's welfare became an extension of the protective stance these mothers employed. In order to provide what they envisioned as the best possible care for their child, they battled not only the health care providers for individualized focused care, they also battled with insurance companies and the reimbursement system in general to get the best possible care for their child. Mothers speak about fighting with physicians, pharmacists, home health care, and the schools to protect their child and ensure optimal care for them. For the most part they embrace this role of advocate because as this mother states, no one else will:

You need to be your child's advocate; because no one else is going to love him the way you do; or care about him; or understand his needs the way you do. And that's a little scary at first. But as you start taking those steps, you'll gain a little confidence.

One of the first areas they might need to tackle were reimbursement issues related to their child's care. Fighting the medical reimbursement system took time and persistence as this mother explains:

I just spent the last year fighting with our insurance company. To the point of getting the Department of Managed Health Care involved. Because he needed to have all of his care centered around one facility.... So I've just spent the last year fighting the insurance company. We finally got it resolved. But it took a year - actually about a year and a half.

In addition to medical reimbursement issues, fighting for help at home was another area of struggle. Arguing for help at home took a significant amount of time as well as persistence and tenacity as this mother explains:

And I called up, and I said, you know I need nursing more. 'We don't cover respite nursing.' I said this isn't respite nursing, this is skilled nursing he needs. When he's in the hospital, I had to argue with them, to tell them when he's in the hospital it takes 3 nurses to cover a 24 hour shift; 3 nurses that have had training, education; some had degrees - to cover my son for 24 hours. Yet, just because we're home, he's really no different, I'm expected to do with no training, no schooling, myself being one person over 24 hours. I said, 'I can't do it; I need a break. I have to have a break.' Well, they argued some more. And I said, 'you know what, he's to the point where you either need to give me some help, or I'm going to admit him to the hospital for a week every so often, and then let you guys pay for him to be there. and give me a break.'

Another mother describes her technique for getting nursing care in the home. "I threw a complete hissy fit and got nursing help in here so I could sleep at night."

For the school-age child, there were issues regarding school which surfaced and needed to be dealt with. Most of the children of school age were attending public schools, although some children were home schooled because the severity of their illness kept them from being mainstreamed. If the mother made a decision to place the child in school, she had to first find a school which would accept her child and then prepare the school for the child, as this mother explains:

I had to find a preschool that would take her. When she started I had to inservice the school. Just try and prepare everybody in the world around her. You know try to inform the teachers. I stood in front of the auditorium and told all the teachers, this is my kid, here is the catheter, here is a set of clamps, if you see any bleeding, clamp the catheter and call me. I had an emergency kit at school in case anything happened. I did a film for the ambulance service. They came and filmed how to clamp a catheter.

This mother and others then not only became the expert in the child's care, but now taught others the care. Because of their expertise and belief in their proven ability to do it best, they subsequently challenged care, which does not meet their standards.

### *Challenging care*

Challenging of nursing and medical care that does not meet their expectations for technique, safety or sensitivity to their child's needs became evident during hospitalizations over the course of the child's care. Home health nursing care was another area of consternation for these mothers. Concerns during hospitalization will be discussed first. These mothers have intervened too many times to avert incorrect orders, medications or dosages and amounts as well as careless technique to not be wary during hospitalizations. One mother described this as follows:

A lot of us don't even let the nurse's mess with the lines, IV lines or anything. You watch them; I watched a nurse who I think highly of the other day, alcohol wipes laying on the table you can pull over the bed. They were lying on the table; she picked them up and wiped the lines. And I just real gently said her name and said 'Don't do that.' I come to the hospital, we get infections.

Another mother described her eagerness to remove her child from the hospital situation on a subsequent visit after she had been caring for her child at home for some time:

I can do a better job of this at home, at least I'd know I was giving meds at the right time and I'm washing my hands and I'm doing everything I'm supposed to do. Because that's my biggest pet peeve, you see people doing crazy stuff. And I'll make sure that she gets everything done the way it's supposed to get done.

This mother describes mistakes as her reason for never leaving her child alone in the hospital:

The reality is we never leave him in a hospital alone anyways. One of us is always with him. Because we have seen too many mistakes and they don't know our kid like we do. You know we see mistakes made on every admission. A resident grabbed his chart and wrote an order for him, on his chart for another kid, for medication he is allergic to. And it even got past the nurses and the nurse came in to give it to him. Until I said 'what are you giving him? No, you're not giving it to him. You can't; he's allergic



to it; get it out of here. Get it off the order; why did they write it? Get this person on the phone; find what's going on.' So the reality is we never leave him.

This mother describes the unnecessary but not particularly life-threatening events she has observed while her child was hospitalized:

Well, because it started out... just some little weird things like she had a PICC-line, and they would come in and draw blood and they would start to stick her. And you know it even said above her bed PICC-line... it was like the communication sometimes wasn't there. And if I wasn't there, not that it would kill her, it wouldn't hurt her, but why having to poke her and... so it was just things like that. They would bring in... she's on TPN no food, and they'd bring her a food tray and set it in front of her. And I'd have to move it. Things like that. What if the parent wasn't there? [If I were the child] I'd eat it. Nobody to stop me if I was hungry. So silly things like that. They came to get her one time for a CT scan or an ultra sound or something, and I said, 'Well, we had it this morning at 8 o'clock.' And just silly things like that. If you weren't there, other stuff would happen that wouldn't be necessary. ... I'd just felt like ... it's not that it would be their fault, it wouldn't be anything that would kill her, it was just why put her through it when you don't have to. And a couple of times – something wasn't compatible and they would come in... and you would be able to say you can't give that with that. No you can't have a cracker, because you're not supposed to have anything... well, when they wouldn't let her have a cracker... I'm sure it's written somewhere. And they'd go back check yep, you're right. Even like dumping the urine. You're not supposed to dump it because of this, you're supposed to strain it. Oh, okay. And so just things like that. If you weren't there [to stop it]. And it wouldn't be anything major, but this is something that makes her life easier, she didn't have to go through it, why do it?

One mother did now trust the hospital personnel where her child has been hospitalized numerous times:

These guys have watched him since he was a baby. And now a lot of the floor nurses have moved on, so now we have nurses that we know in OR, recovery, same-day surgery, and so everywhere I go, I see a familiar face. And so that is very comforting.

But when the prospect of a bowel transplant in another hospital in another state presented itself, she said:

I wouldn't leave him for a second. Cause I don't know them. You don't just automatically trust people. That develops over time. And you know, at some point, I might feel that I could leave him there, but at this point, I don't know them at all. And I don't know if they'll listen to me. And that's the biggest thing, that you don't know if they hear you.

The result of mistakes that these mothers caught to narrowly avert disaster or that personnel made that did result in some type of harrowing experience for the child had left them feeling that indeed no one could be trusted to care for their child unless closely supervised. They also developed a wariness of any nursing care performed in their home by outside providers.

Some mothers, because of insurance coverage or the amount of care their child needed, were able to contract for home health nurses to give them respite for periods of time each day or hours each week. This mother gives her view of the characteristics she seeks in a potential home health nurse:

Maybe call me ... I don't know what for a mother, but if they didn't present themselves with a nice appearance and their hair combed, and they looked nice, I didn't want them touching her TPN or her lines. So it's like, I don't know... maybe I was not fair but I just felt like instead of dealing with a big huge infection, that someone didn't clean right, then it was better off that way... I would tell my husband, I said maybe I'm a bitch, but I said it's better for (my daughter) if I am a bitch and protective, that someone doesn't give her a huge infection. We have to treat her with beaucoup antibiotics; have to take the line out, and then the end result, she gets yeast because we've had to give her so much antibiotics and then my baby is gone. . So I said I'm sorry, if they don't pass that no-scum test they don't touch nothing.

Another mother described her view of home health nurses:

You know we do have home health nurses, but I don't know where they get them. I don't know if they find them on the street. Yeah, I wasn't, I just wasn't pleased with them." These nurses aren't...I mean they're definitely second rate. I don't know where they get them. They don't know what they're doing; I don't know if they just don't work with kids, or... I mean you might as well let a blind person take care of your child, because they don't even know what they're doing.

The home health agency also contributed to inept care in the mother's eyes as evidenced by this comment:

I caught an error (with the home health agency). I was mixing her bags and just happened to notice the total caloric value of the entire TPN bag, and so I called and said 'you know I thought she was supposed to be on 1100 calories and that says like 700.' So it ended up being that they were mixing the TPN incorrectly.

Among the mothers who utilized home health care or respite care, there was usually one nurse who had been trained by the mother whom she now trusted. But even then, the trust might be limited to certain tasks without the risk of others. The bottom line was things needed to be done her way and if that couldn't happen, the mother would rather do it herself.

### *Controlling Care*

In this role of "mother knows best", she was reluctant to let anyone else perform the complicated care she had learned and perfected over time. This included her husband and the children themselves even when they became old enough to learn. This mother explains:

I didn't feel like I could get away or that I could trust anybody with his care again. That's a lot of responsibility to hold on your shoulders, because you don't think anyone else can do it. It's real hard to let go.

Another mother explains how difficult it is for her to let her daughter perform her own care:

Oh, now it's the independence thing. Now she does all of it herself (her care) and I don't know if she's done it correctly. Cause when I did it all, it was very sterile. (Then) she had a series of infections. (I would think to myself) Did she break technique? Did she get lazy, didn't wash her hands? Cause I was always meticulous. (Maybe), I'll just do this. I worry sometimes because she doesn't always do things the way she is supposed to. The other day she came back from the pool and she got her dressing all wet. (And I said), 'Go get your shower, get washed up, is your dressing wet?' I'd never have left it sitting for another whole half an hour. If it were wet it would have come off immediately.

And when speaking about her husband performing the care, this mother states. "It's one of those situations where you got to trust each other to do it. Because you want to do it all because you want it done right. You know."

Many mothers also expressed the risk of infection of the line as too big of a responsibility to entrust either to the child or to siblings in the household as this mother states:

Her sisters know, but they very seldom do it. But they know the steps. They have done TPN hook-up; they have done flushing more often than hook-up. But for some reason, we always felt that it was our responsibility and it's too big a responsibility for her sisters if something would happen, we'd rather it be us than her sisters.

A result of this advocacy, challenging the medical and nursing care and controlling care, these mothers risked alienation of medical personnel and even felt threatened with removal of the child from their care.

### *Risk of alienation*

These mothers remark that the risk of alienation is always high when advocating for their child and challenging the system. This mother explains:

Well, I still have trouble standing up to staff in the hospital. You know... and it's the hierarchy of knowing who to talk to and when and stuff... And then you run the risk well, if you totally alienate these people, they can take your kid away from you nowadays. And so it's like how do you do this? It's really difficult.

This mother explains her experience with threats to take away her child:

And then they do the thing, 'Well, if you can't take care of him, I'll have to have him placed in a home.'

In summary, this category, *Challenging the System* depicts the struggle these mothers endure in their continued protective care to advocate for their child in various arenas. It explains their efforts at advocating for their child, challenging the care given and ultimately controlling the care. Often another reason for challenging the system is tied in with the next category, *Promoting Normalcy*.

#### *Promoting Normalcy*

Although the first months up to a year might comprise a learning period for the mother, she was anxious from the beginning to promote as normal a life as possible under the circumstances. Promoting normalcy can be thought of as another way in which these mothers practiced protective care with their children, as they desired acceptance of their children in the world at large despite their disabilities. Promoting normalcy encompassed all of the tasks these mothers performed to promote the social acceptance of their child and to help their child reach as many developmental milestones as possible despite a very unstable condition. This mother equates the thought of this child as being normal with denial, by saying:

But really... I am very good at normalizing, and it's... a severe case of denial is what it is. And all of us do [who] have kids that are chronically

ill. We just kind of go into hibernation mode or something, and pretend that nothing's wrong. And then when something happens, all of a sudden we get shaken into reality like oh my gosh, I have this fragile kid. I mean he could throw a clot out the end of his line today and be gone tomorrow. And so then you live at that height of emotion and fragility for about two weeks and then you forget again. And then you fall back into that neutral mode again... well, he's... 'what do you mean? He's fine there's nothing wrong with him.'

Other mothers wanted the child to know they were "special" but still like every other kid. One mother conveys these somewhat conflicting comments in the same breath when she states, " I want her to know she is like every other kid. We tell her all the time she is special; she has a special belly and a special chest."

Another mother explains this concept with these words:

You know, he is not a disease. He is a kid; he is a normal kid with some abnormal problems. And if I were to treat him like an illness, he'd have nothing. So I have to treat him like a normal kid and deal with the problems as they come, but not focus on them, and not concentrate on them. As much as I can.

These efforts at normalization usually began once the mother calculated the risks of allowing some flexibility in the child's life and accepted the uncertainty that the condition carried with it. Despite the child's condition, enforcing discipline was one way that they could work to ensure the acceptance of their child. Issues of food and feeding became a large part of their lives. They struggled with issues of food and feeding if the child was an infant, beginning with bottle or breast-feeding through the frustrations of feeding and eating behaviors to adolescence. Depending on whether the child could eat and wouldn't or wanted to eat and couldn't, they coped with the consequences of that behavior. This section will examine the facets of promoting normalcy in the lives of these children. This begins with allowing flexibility.

### *Allowing Flexibility*

In order to be able to promote normalcy in her life as well as the child's, each mother had to learn to be flexible with her child's care, as this mother states so well:

Don't let (your child's illness) rule your day. You try and let your child be as normal as possible. If you want to have your child hooked up for 13 hours and sleep an hour late, then do it. You don't have to be on a strict schedule. This is your life at home.

For some mothers that meant not always doing things 'by the book', but developing short cuts to save time, or allow the child to experience normal childhood activities like camping trips, overnights and other time with friends. These mothers learned to juggle the fluid requirements of the parenteral nutrition so that the situation did not rule the child's social life. One mother explains:

I rarely ever say, we have to be home at a certain time because you need your fluid.... I will cut him short on his TPN sometimes. I'll cut him short 200-300 cc. sometimes so that he is allowed to do what he needs to. You know if he is at a concert or he's at a friend's." "And the days that he gets fluid ...I sometimes manipulate those days and save them for the weekend. So if he wants to go overnight I can run a liter before he goes and then I run a liter when he comes home the next afternoon.

Another mother describes her spur of the moment decision making this way:

And we have... you know, said we're going to hook up tonight and then oh, no we're not, and put it back in the fridge... it just depends on what his friends want to do. Because I feel like, if he wants to go somewhere, he's going to go...

To maintain her own normalcy, this mother "cuts corners" this way:

You know, it's okay if he doesn't get his dressing changed every two days. Sometimes he'll go every three days or even every four days. If the dressing is clean and dry. But at one point, I was like no, this is what it says, we need to do ... you know, I have to do dressing changes. All right, it's 10 o'clock I have to do it. And I think no it doesn't have to be. Just being able to be flexible to what's going on.

Flexibility then was a key to promoting normalcy, but a corollary to the flexibility, was accepting the uncertainty that accompanied the rapid changes in condition these children could develop, disrupting many plans.

### *Accepting Uncertainty*

Uncertainty became a way of life for these mothers and in the midst of promoting normalcy they had to always keep in mind the tenuous nature of their child's condition when planning activities. This mother describes it this way. "I always had to keep in the back of my mind that our plans could change abruptly, because he could get an infection or something could happen." Another mother explains how difficult it is to make long-range plans:

You just don't know. How long are we going to get this time? Even when we are trying to make our plans in November. Now we've got to keep her healthy through November, you know. Cause you just don't know... you don't know what's going to set her off; what's going to set it all off.

Still another mother describes her frustration in not being able to do any spur-of-the-moment activities:

It's slowed us down. And I can't anymore just go, 'okay kids wake up, throw some clothes on, we're going to go here.' And that's what we always did, you know. 'It's gorgeous. Let's go to Rainbow Lake, let's go on a picnic, let's do this, let's do that.' And you can't do that. You can't get up and go. You have to stop and see how he is feeling. We haven't had a camping weekend in the last year and a half that hasn't been interrupted by him being sick and having to take him home and at least one of us needing to stay with him.

Promoting normalization began very often with efforts at fostering acceptance of this child.

### *Fostering Acceptance*



Three key components were identified by these mothers to ensure social acceptance of these children. Behavior was the first key to acceptance and one way they could control behavior was through discipline. The second was appearance and the third was the ability to participate in age-related social activities. These components will be discussed beginning with enforcing discipline.

*Enforcing discipline.* Most of these mothers believed that if their child was to be accepted in the world, their illness should not be an excuse for bad behavior. The child needed to be disciplined and be expected to be "a working member of the family." One mother expressed her views this way:

She is expected to mind. And she is very hardheaded; she is very strong willed; that's why she is alive. But she is expected to mind. She is expected to do what we ask her to do. And I treat her as a normal child. I don't want a brat.

Another mother echoed those comments with these:

I 'm strict... And kids need discipline; kids want discipline. I also want her not to act different than other kids; to not have the attention brought to her because she's a spoiled little brat. Because she's a poor sick girl. I want her to know she's like every other kid.

One mother of a young child did have difficulty enforcing discipline because of guilt feelings as she expresses here:

I don't punish (her). I'm sacred to death to punish (her). I'm afraid if I did tomorrow she'd pass away, and I'd say ' Oh my gosh, I didn't read her that book.' Or I took her TV away, or threw her in a corner.

Her reaction was not typical however as most mothers did want their child to be accepted not rejected because of poor behavior. Another way that mothers promoted normalization as identified earlier was encouraging social activities with friends.

*Promoting Socialization.* Many mothers worried about their child's social life as they often could not attend school and spent long periods of time hospitalized. This worry was more pronounced during the adolescent years when most mothers appreciated the value of the peer group on their child's development. This mother expresses her concern this way:

I worry about his social development and that he is not having a normal life. I worry about that he is too dependent on me and trying to find a balance between baling out on him and I want him to grow up and have a life. And he's 16 and he's not 16 emotionally. And you couldn't expect him to be. But that's my biggest worry. I guess the emotional, social area... because he hasn't been able to go to school.

Another mother expresses a similar concern:

I worry that he spends a lot of his time alone. And he has great friends. They come to visit him when he is sick. You know, when he was in the hospital they were there. They call and check on him if he misses school, but it's not the same. He... last Saturday was homecoming dance. And he didn't go to home coming; well, he couldn't have; he had surgery Friday for the Hickman. But he couldn't have gone to the homecoming dance, but even if had been well, he wouldn't have gone. He's small; he's just... he's not socially outgoing at all, so he wouldn't put himself in the position of asking a girl that's taller than he is. So in a lot of ways, he has excluded himself socially from some situations where he would be a little bit uncomfortable, and that worries me.

This mother explains how they promote social activities:

Just try to keep him active with his friends. And there has been friends when it has been really hard for him because one of his friends is ... they've been friends since they were in kindergarten. He was over in an area that is on a lake, so their backyard is this huge lake. And so they would go over to the lake and go swimming. Well, with the Hickman you can't swim. Or somebody had a swimming pool or wanted to ... when this first started going on, when he was first diagnosed with it, and everything, when he first got sick, he played soccer. And he played baseball. And all of a sudden he couldn't play baseball and soccer anymore. And we wanted him to be able to play baseball, but it was decided that with the Hickman it probably wouldn't be a good idea.

because of the... danger involved if he got hit in the chest with a ball or something. So that was very hard because his father is pretty much a baseball person, and I think he liked playing soccer more than he liked playing the baseball. But all of a sudden to have everything pulled out from underneath you. So we were always constantly do you want to go to the movies? And so he would go to the show with his dad a lot, you know. Cause they would go see movies that I didn't care to see. Do you want to go walk around the Mall? Anything to just keep him ... he has a group of friends that stay pretty close to him. And when he was sick or whatever, they always made sure that he was okay. They included him in their plans with whatever they were doing; they included him.

Another mother stresses how she promoted the socialization of a younger child:

We make sure that her school time - there is enough time with socialization with the kids in her class. She has always gone to a Special Ed class, for the severe and profound. So it's... if we're going to go to McDonald's we're going to take her with us. My grandchildren come over and play with her; they live right up the street a little. And they... I don't think they realize that Rhonda is not like other kids. Sure, there's IV tubing off her enteral pumps, all over the floor. I fought really hard to find long tubing, so that when she is at home, she isn't tipping the pump over. I found one piece of tubing that was 16 feet long. And we added a couple of the smaller tube extensions, so she has freedom of the whole ground floor. She can go where she wants. It's not like she has to ask us, or... come and get us to let her go further. I swore once she went on enteral feeds and then on TPN too... we were going to arrange the schedule so that her progress was not impeded by having to be on these feeds. They had stressed that we do TPN during the day, but you have no mobility doing that.

In addition to promoting socialization, these mothers realize that appearance plays a part in their child's acceptance socially.

*Appearance.* Appearance of the child affected how he was treated and accepted socially. This mother describes her efforts to improve her child's chances for acceptance:

The most overt way that I try to make the world accept her (is to) keep her haircut real cute and fix it nice, put beautiful little bows in. I don't care if the bow costs me \$20. So always in nice clothes. So if I make her beautiful and present her to the world and I find that she is more accepted.

Even the doctors compliment her. 'Gosh, you look so cute today all dressed up.' That makes me feel good, like they've accepted her.

Another mother explains why her son's appearance may keep him from social acceptance:

Big impact socially. The PICC line in his arm was really hard, because he had to wear long sleeves to school. And because of his illness he hasn't grown, so he is very short. Being a junior in high school he's 5 foot tall. And right now, he's 93 pounds. So he is obviously different than his peers. And it really bothers him... So it's really impacted him socially. Which is heartbreaking as a mom.

### *Normalizing feeding and eating behaviors*

A wide range of feeding and eating behaviors presented in this study. The capability of eating was present in most of the children, but many of the children who were allowed and encouraged to eat despite their dependence on parenteral nutrition at least initially were not interested. Many of the children had developed food aversions or had unusual habits once they began to eat. The children who wanted to eat, but had been placed on gut rest were not allowed to eat. These mothers had to find ways for their family to eat without tempting the child who could not. All of these variations presented great consternation to mothers who depend on their child eating for much of their gratification in the mothering role. These mothers then had to adapt themselves, their families, and other social situations to this altered pattern of feeding and eating.

This section will address these variations and how these altered eating patterns were managed. The various eating or non-eating patterns will be described, followed by the reaction of mothers to these altered behaviors that helped to normalize the life of these children and families in a world where eating carries much social significance. Promotion of normalizing feeding and eating behaviors starts at the very beginning with

feeding and attachment, proceeds with battling feeding issues in general and includes, catering to eating preferences, normalizing mealtimes and making allowances.

*Fostering Attachment.* If the child was a newborn and became dependent on parenteral nutrition shortly after birth, very little opportunity, if any, existed for the mother and child to develop a bond through feeding. Despite the fact that most mothers worried about whether bonding would take place in these instances, according to them their fears were unfounded, because of the simple fact that although not feeding their infant in the traditional way, they spent perhaps more time holding the child. The time they spent with the child doing other care actually seemed to forge a greater bond than they expected, but perhaps later. This alternative did not negate the fact that not being able to feed the baby was a source of sadness for these mothers of infants. One mother put it this way:

Oh I felt bad when the baby was born. I had her for a couple of days and I was breast-feeding, the milk came in and I didn't have the baby. And they took her from me and I'm pumping for milk, cause they said when you get her back after she has the surgery (you can feed her), so I had little bottles of milk home saved. And I was thinking, 'oh, we didn't bond; we're not going to bond right.' Well, you're not in the beginning. You know her and I are like Frick and Frack. It's a nice relationship; she makes me laugh. We have a great relationship; we're very close.

As the child grew older many mothers actually felt the child was clingy, very close and "really emotionally connected." But the feeding was missed as this mother states, "She was in the hospital so much that first year and I spent a lot of time in there. And I had nothing else to do, so I just held her. So I think I did bond with her that way. But still not being able to breast feed (bothered me)." Another mother actually felt that

her child woke up every 3-4 hours to be held, despite the fact she was not being fed. She describes it this way:

When I took her home, it was really interesting, how babies every 3-4 hours want their bottle; she wanted her pacifier and held. She wanted the bonding of that. And so even at night, she woke up at least once in the night just needing nothing but a pacifier and 5 minutes of holding.

On the other hand, struggling with a child who was not on TPN initially, but proved difficult to feed brought feelings of anger and nonattachment as this mother explains, "I felt angry and unattached to her when she was not eating I never got to really (nurse her). I really didn't. I force-fed her for the first 2 1/2 years of her life."

Children who became dependent on parenteral nutrition later in life, may have had a closer relationship with their mothers than if they had not become ill as this mother describes.

I wonder if we would have stayed as close because if he hadn't of gotten sick, he probably would have continued with the soccer and baseball. So I don't know if we would have had the closeness that we had if he hadn't of gotten sick.

As the child grew and developed, mothers had to make concessions to the eating or non-eating habits their children developed. For the child who didn't eat and had no desire to eat, mothers made an attempt to normalize mealtimes.

*Normalizing mealtimes.* Despite the fact that most of these children did not eat while on parenteral nutrition, most mothers insisted the child come to the table at mealtime. The child might leave after a prayer, stay and socialize, play with the food or taste or lick the food. Sometimes they might eat as this mother describes:

I like her to come to the table, whether or not she is eating. I like her to come to the table, but it depends on how she feels, if she is really sick, she

won't come to the table. If she's not, she'll sit at the table. And most of the times she'll eat. Like she's been feeling really good this week, so she's been eating every day.

For another mother with a big family, having a child at the table who wasn't eating, created problems as she explains:

We usually have it that she has to sit down with us until we have grace and then she may sit with us if she wants to. If she wants to leave the table she may. And right now she prefers to leave the table. For a while she sat with us. And that was kind of provoking sometimes. Because the other family members want time to talk also. She wasn't eating, so she spent the whole meal hogging the conversation and it was kind of hard for her older brothers and sisters. So in a way it is nicer if she does leave the table. She'll slip into a book then, and we can have mealtime without her.

For the child who wanted to eat, but was forced to abstain from eating to rest the gut, mealtime became an unpleasant time. Food was such a temptation to that child that it seemed cruel to eat in front of them and so disrupted the whole household as this mother relates:

And she really wanted to eat and that was hard. Cause our whole family quit eating in front of her. We wouldn't eat in the house, we wouldn't cook in the house, because it smelled and she was starving, so we couldn't eat in front to her and that was really hard. We would sneak out, go over to neighbors or sneak out to a [a fast-food restaurant] at 10-11 o'clock at night. We wouldn't eat or drink anything in front of her. She was really hungry; I mean really hungry. To the point where we didn't want to leave her alone because she said she would not get into anything, but we didn't know if she would or not.

*Making allowances.* To make up for food intake, some mothers had devised alternatives to food. For some, a toy was given to the child when his siblings were eating a "Happy Meal" or going to a restaurant for dinner. Or it might be a big bowl of ice or Sno-cones covered in Pedialyte or Gatorade. For others, substitutions for food included a

trip to the lake for canoeing or fishing and for still others it was replaced with affection - hugs and kisses.

Some mothers went to great lengths to cover up the fact the child was not eating by ordering food for a child at a fast food drive-through so the attendant wouldn't think she wasn't feeding her child. Others would try in vain to inform a waiter or waitress, their child was not eating only to be questioned in detail, as this mother explains:

It gets hard at restaurants, the waitresses say, 'What can I get for him?' [I say] 'Nothing he's just fine with his ice. [They say], 'Are you going to share, do you need another plate? [I say], 'No, I don't need a plate for him, he's fine with his ice.' And she'll say, 'well do you want to order for him?' and [I'll say], 'no, I don't want to order anything for him.' Occasionally I'll have to say he doesn't eat anything by mouth, his nutrition is through his IV. And then they say, 'Oh, I'm sorry', and then they'll start asking other questions. Other times they'll just walk away. Probably 75% of the time they're just fine. And they'll just say 'okay' and they'll figure we'll share. It gets a little weird when we are in a buffet, because they think we're just trying to sneak his food without paying, but normally we have to clarify that he doesn't eat, he will just have ice.

Many emotions surfaced here surrounding the various feeding/eating issues, which are a part of this child who does not normally ingest food.

*Emotions surrounding feeding issues.* Most mothers expressed a myriad of emotions connected to feeding/eating behaviors or expectations, which did not materialize. These include frustration, helplessness, sadness and gratification.

Feeding seemed such an integral part of motherhood that most mothers felt very frustrated when their child either could not eat or would not eat by mouth. The only exception to this was a child for whom oral feeding had become a painful event for both mother and child. As this mother relates:



It is very difficult as a mother not to be able to feed your children. But at the same time it became very clear, very quickly that if he wasn't fed, he'd feel so much better. So then you feel guilty trying to feed your child, because when you feed your child, now he gets sick. Mothers usually pick up on this first. But doctors who are not familiar with the disease think the worst thing you can possibly do is remove food. Now be a mother and be in that position where the doctor's telling you you're bad for not feeding your child; and you know that when you feed your child, your child gets very, very sick. Hurting, screaming, vomiting, diarrhea. I mean this horrible torture. And how does this mother feel? It's difficult to not to be able to feed your child and to know that if you feed your child you make them sick.... And it makes you feel awful; your child needs food to survive, it is your job as a mother to feed him. But you're making your child sick.

Other mothers though were devastated by the child who wouldn't or couldn't eat.

All of these changes around food feeding and eating could cause great frustration and consternation for the mother for whom feeding was a source of gratification.

Some situations make them feel helpless as this mother illustrates:

I'm a control person. I've always been the leader in charge, who takes control of everything. *And to know I could not make her eat.* It is... you feel so helpless. You feel like your whole world is crumbling down around you because you can't do this one simple thing that people take for granted.

Some situations make them sad, because of their own relationship with food, as this mother relates:

And I grieved more that he couldn't eat than he did, because he has always been a kid that just wasn't interested in food, and I have a definite relationship with food and he could care less. I love to cook and I'm a real nurturer and homebody and I used to bake bread. I'm a gardener, sewer, cooker kind of person. I miss not being able to feed him on holidays; Christmas dinner, Thanksgiving dinner, birthday dinners. Food is such an integral part of our socialization and celebration.... So I think it is harder on me than it is on him now. Cause he never really liked to eat anyway.

Another mother describes how she wanted to comfort her baby with food and the frustration she felt:

It was really hard for me not to give her a bottle. When she was fussy and crabby, I just wanted to go get that bottle and put it in her mouth and rock her; nice warm bottle, nice soft slippers and put her to bed. And it was really, really hard not to do that. I wanted to fix that nice warm bottle in the evenings when she was fussy, tired and didn't know what she wanted. And they didn't let me.

The mothers of children who had not been eating by mouth and who now began to eat experienced tremendous gratification. This mother relates the gratification she as well as other felt when her child began to eat:

It was so gratifying to see him eat. And everybody felt that way. I have more pictures of him eating. I have pictures of his first sub sandwich. I have pictures of his first pizza. I have him eating pesto spaghetti... and it's hanging out of his mouth. Yeah, I have a lot of pictures of him eating. You know with food all over, spaghetti sauce all over his mouth, everything. We would all just sit and stare at him eat, because it made us feel so good to see him eat.

In summary, this category of Promoting Normalcy explains the desire of each of these mothers to provide opportunities for normal development of their child, by promoting acceptance of their child through behavior, through social activities, and through appearance. Normalizing feeding and eating behavior was accomplished through fostering attachment, normalizing mealtime and making allowances. Various emotions expressed were directly related to feeding difficulties or rewards. Through all of this protective care, these mothers fought to keep their life in perspective.

#### Putting Life in Perspective

As these mothers watched over their children, they continually put their life in perspective. They acknowledged their feelings of anger and guilt, lost opportunities and

being tied down but had developed ways to look at the world with different eyes to keep their balance. This mother describes this change best:

You know when you have a child like this your whole life changes. Your whole perspective changes. Things that would have shocked me years ago... even 4 years ago... 3 ½ years ago... now are oh, big deal. No big deal. It changes your whole perspective. It changes people's perspectives around you; how you're treated. How people look at you. The church... your family.... And it changes your entire life. There is no going back to a normal life after you have had a child like this. No matter even when they are almost normal; or they are normal your life is changed. Because your perspectives on what is important has changed.

Recognizing anger and guilt and lost opportunities, the mothers worked at ways to find respite and acknowledged support systems, which worked for them. Finally they contemplated the future by holding out hope and preparing to let go while at the same time recognizing the child's mortality.

#### *Coping with Lost Personal Opportunities*

One of the consequences of performing this overwhelming care alone was the fact that these mothers felt tied down and consequently reflected on missed opportunities in their lives. The feeling of being tied down is explored first.

The constant never-ending routine, which had to be performed every day at specific times forced them to be at home every morning and every evening, as this mother explains:

It was really hard for me in my early 30's. I had to be home every night at 6 o'clock. You know, every night. There was no going to the church's women's meeting.

Another mother states:

[It was hard] always having to be available, if I'm out in the evening, I have to plan... I fix it [the solution] before I go, or I fix it when I get back. [And sometimes] I'm tired and I just don't want to do it.

There are no "off days" as this mother explains:

This is difficult to do for 365 days a year and not have a resource for when you get the flu or anything else. It's just really difficult. Everybody has a day when if you get the flu or something or an 'off' day and it's hard to hold your head up and do something that you have to be meticulous.

If her husband has been taught the care, occasionally, she might get out without him or vice versa, but they did not routinely go out together, as this mother states, "We' ve been away one time, I think ... One night we' ve been away (in four years). Since he went on TPN - just the two of us, and we left him with a nurse. " If they do get away without the child, most of the time might be spent worrying about whether the child is okay at home, as this mother explains:

My husband and I went out of town one weekend just the two of us... just to get away from it for 48 hours... just to get away from it. But your mind is constantly going back to... I hope Virginia can get the thing primed. I hope she ' s not having to ... in the middle of all ... in your thinking... oh my God, I wonder if everything is okay.

If a vacation is planned with the child, it becomes an exercise in logistics to pack all the equipment the child requires and as this mother explains, only the location changed as described by this mother:

And I think it was good to get away, and get out of the city and everything. But we took everything right along with us. And so we really didn' t get away. We just took everything from our house to the hotel room, and had the TPN and everything right there with us. So we never really escaped, we just changed locations.

Some mothers expressed a wistful feeling for what might have been or what they might have missed out on. Some of these mothers had put their careers on hold and

imagined the position they might now occupy had they not stopped it all or lost their jobs to care for their child as this mother relates:

I've wondered what it would be like to have a normal child. I lost my job because she was so sick. I think I would have been a RN and I would have had other children. I would have been in some administrative job in a hospital. My plans were to go to school and be a RN.

Other mothers reflected on the time that could have been spent with a sibling and what she and the sibling had missed out on. For the most part though, these mothers looked toward the future and refused to dwell on the past.

### *Experiencing Anger and Guilt*

An obvious consequence of the intense watching over and the care that became never-ending was anger and perhaps subsequent guilt. Anger might be directed at the situation, the child or the physician. Sometimes the anger is the result of fatigue.

Anger is most often directed at the situation rather than the child or a specific person, as this mother points out:

I get angry very often. I never take that out on anybody. I try to project that more into better ways of letting that out. I get real involved in things as a way to deal with that anger. Yeah, I get mad. I get mad because my kids can't eat. I get real mad that my son can't even drink. It makes me angry we have to go through it. Although I do get angry, I can usually look at the bigger picture and find a more optimistic perspective to look at things.

More often than not, the trigger for the anger is fatigue, as this mother explains, " I get angry sometimes when I'm tired. I just let go." Or this mother who states:

Yeah, sometimes I get angry when at 10 o' clock at night, and I haven' t mixed the bag by 8, and he is due to be hooked up by 10:30, and I' m tired and want to go to bed. And I can' t go to bed; I have another hour worth of stuff to do. I have to mix his bag and set everything up and that' s a half-hour. And getting him changed over and doing all his care between

his TPN bags, his enteral set up, his cleaning GT, the whole thing. Like I just want to go to bed, I just want to be mom; I don't want to be all this stuff. I want to be mom like I did for my other kids. And I shouldn't have to be doing this kind of stuff. But then I get over it. I get angry, when he gets sick. You're angry because it's happening and there's nothing you can do to change it.

Most often the anger takes the form of crying or yelling at " anyone who happens to be standing around at the time." Occasionally the anger is directed at the child or the medical personnel:

I would just scream at her 'you have to eat, you're going to die; you have to eat'. I feel like I lost total control and was doing things out of desperation, because I knew she was going to die.

You know, I found myself being very short-fused at times in the hospital. You know, when people come in and they just ask stupid things. And it's like how many times do I have to tell you, they argue with me, about his medication. You know one being with it being one of two different meds. And they're saying it's a different med. It's like get your book out, and look it up and see what it is for. And they're adamant and saying no; this is what I'm going to order. And he's not on that. It's a completely different medication. You know, when they walk about with their pompous attitude and not even say you're right or anything. So yeah, I get angry that I have to deal [with], I have to explain this to everyone that I come across in the hospital who happens to be new that month. It gets really old. And I get angry when they try to come in and change his routine to fit into their routine. And that's not the way it is. He has his routine, and they need to work around his routine, for his infusion and stuff like that. You get angry. I'm not typically an angry person, but I do get feelings of anger.

The second consuming emotion was guilt. Guilt surfaced on occasion and could be derived from the child's condition or proceeded by anger or punishment. Sometimes the guilty feeling is a result of what the mother may perceive as inattentive care resulting in an untoward event for the child, a poor decision on her part, or an inability to spend time with her other children. This mother summarizes all of the guilt feelings at once:

I feel guilty if I wake up in the morning and the pump hasn't been running right, and I didn't catch it. I feel guilty if I've gone somewhere and left him with my husband. Occasionally he is doing fine. Left him with my older daughter and she called me and said he's not feeling good. I felt guilty that I left him. You know, not that I could have done anything if I was here. I feel guilty that if he gets an infection is there something that I could have done better. Was there another step that I could have taken above and beyond normal? You know, is there something that I did that I didn't know, that caused him to get sick? I felt guilty when he was born and was struggling the first couple of days. I couldn't even... couldn't rub him because it over stimulated him. Like oh my gosh, you're... laying here and you're suffering and you know, is it something I did or something I didn't do. Should I have done something better? So, yeah. And then when you get bonehead doctors making comments to you and saying you know, what do you mean, you're only doing this? You're not doing this step too? I didn't know. I feel guilty when I find out things that I should have been doing that I didn't know I was supposed to be doing. Should I have scrubbed a little bit longer? Should I have washed my hands 3 times instead of two times? We do all we can, and in reality I know that there is nothing I could have done. But there's still that feeling. And there is guilt to the other kids - I have 4 kids I have to leave when he goes into the hospital. So when I call them on the phone and my youngest is crying and saying, 'Mommy, I want you to be home. I want [my brother] to come home, I miss you.' I feel guilty because I'm walking out on my other four kids. But I know that [my son] needs us there. He needs me; he needs my help, he needs one of us to be there. So yeah, I feel guilty because I miss things with the other kids. If they're doing something, I miss out on. I didn't take my son to get his hand casted; I had my best friend do it. You know, jokingly we call her the new step mom anyways, because she is my best friend, and the kids are with them when [my son] is in the hospital. She truly is a second mom for the kids, and I couldn't ask for a better one. But I feel guilty because she had to take my other son to get casted; and it wasn't me; and it was something we should have been doing. Because my husband was working, and I [couldn't be there.]. So in reality, I know that there is nothing that I could do to prevent what is going on or make things better, but ...

Some of these mothers felt some guilt for the cause of the child's condition as these mothers explain:

You know, I felt guilty a lot at first. I wanted to know why. I wanted to know ... You know some people would say it was the estrogen and the birth control pills.

They say with short bowel, they don't really know what causes it. Especially when it's at birth. So what if you didn't exercise your first trimester, would that have been better? And they would say well, maybe it was environmental. You know when you give birth; you are ultimately responsible. It's inbred. I don't care what they tell you. You feel that way.

But I did feel guilty because we thought he had the flu. So we're at home and what's happening is his intestines mal-rotating. And he's in pain and he's always been in a lot of pain. And I've stayed up with him like you know... I can't remember. And we called, we called and they just said nobody urged us to come in, and finally I called and said look it, we're coming in. Cause nobody knew. I mean even they were going to admit him for dehydration just for observation. And I wasn't even here. My husband had brought him in. So then they got him, but I ... and I try not to go there, but every once in a while, it comes up and I go back, and I think what if I would of brought him in 24 hours earlier? You know, but that's fruitless. No, I don't know what would have happened, and you do the best you can. And no... so but sometimes every once in a while that comes up. I think man; if I would have just taken him he wouldn't be... this wouldn't be his life now. I mean it was one of those defining moments, just ... Yeah, but you can't go there. So I pretty much... Yeah, I pretty much say no I'm not going to go there, because I worked through it intellectually and so I just fight it off, because...

For others it was a result of anger at or punishment of the child as these mothers state:

I go through guilt if I yell at [her] or if I say, 'you've not been very good this week, we're not going to Chucky Cheese.'

I feel guilty for getting angry at her before we came to the hospital and I would scream at her, 'you have to eat, you're going to die, you have to eat.'



### *Finding Respite*

Realizing these missed opportunities and strong emotions were the result of this intensive care over time, these mothers sought respite to avoid physical and mental exhaustion and/or illness and "burn-out".

All of these mothers had found a way to remove themselves from the situation when feeling overwhelmed or at regular intervals. For most it was a simple activity that perhaps only removed them from the situation for a short time, but renewed their ability to face the tasks again. One mother just steps out on her deck and watches the birds, many go away to shop for short intervals, some read, watch TV, go to a movie, or surf the Internet. Only a few of these mothers were able to have an outside job, but for those mothers, working away from home was a respite. For others a nap not only restored their energy, but also was an escape from reality. Some exercise or garden and some pray. One mother describes her "mindless escape" activity of playing cards:

A lot of times, I'll say, 'okay this week I have to have a Euchre night.' When you're playing cards and counting, you can't think about (what's going on at home). You can't do two things at once. And if you do this at a Euchre tournament, they're going to kill you. I need a mindless total escape activity that's only 2 hours, maybe once every three weeks. That's kind of like a life preserver. When I say I need it, they [family] all know I need it. Nothing is going to stop me from getting there. When I know I need it is when I'm not able to fluff things up and it puts things back in check. It changes priorities, puts me back into perspective.

Only one mother described hospitalization as respite for her, as the other mothers felt an overwhelming need to continue their vigilance and care even when the child was hospitalized as they had developed a distrust of the nursing and sometimes medical care

as described earlier. This one mother, however, was very blunt about her enjoyment when her child was hospitalized as evidenced by this quote:

I think at this point I stay with him [in the hospital] for more like emotional support. And also for me... this is... a sad commentary on my life... this is a vacation. I can sleep all night, because the nurses do everything. They measure the ins and outs. And I have a very comfortable room; I bring my sleep clothes, my rocking chair, my music, and my novels. And I never get to sit around at home and read novels you know. ... And then I get to go shopping here in town. And so I come to the hospital for fun. And I've been in and out of here for 15 years and I know a lot of people and have some real good friends here.

Some mothers had either employed a respite nurse they trusted for longer times of respite during the day, or taught someone like an older sibling the basic steps of hooking up or unhooking the child from the parenteral nutrition so that they could have a little more freedom on occasion. Many had the help of their husband usually willingly, although they had taught the husband the care, only rarely had the husband been involved from the beginning.

Establishing support systems was another way these mothers averted some of the consequences of this intense care.

### *Establishing Support*

These women were very proactive in building their own support systems. They emphasized repeatedly the importance of support for all mothers in this situation. The Oley Foundation, a national support group for individuals and families with a member dependent on either enteral or parenteral nutrition had been recommended to many of these mothers upon the diagnosis of their child. A yearly conference drew some of these mothers together for what might be their only trip away from home, but the child almost

always accompanied them. In addition, many mothers had the support of other mothers through an online Internet group that had been organized. The church and their faith were a source of support for many of these women. Other sources of support were spouses, neighbors, co-workers, nurses and friends. In general families were not very supportive. The most common reason for this lack of support was fear that family members had regarding the child's fragility and possible demise. The common thought was that if they denied the existence of the child's problem, they wouldn't have to face it. On the other hand some members of the extended family were very supportive emotionally, but could not be counted on to learn the care or be supportive on a daily basis either because they were geographically removed from the situation or fearful of the central line.

### *Contemplating the future*

In contemplating the future, these mothers expressed some worry about what the future might bring, were occasionally hopeful for a better life for themselves and their child, but realistically recognized the possibilities of mortality. As is the case for all mothers, as their children became older, these mothers were faced with separation issues with a child to whom they had become strongly attached. This mother explains how difficult it will be for her to "let go":

It's a huge issue for me now because she's going to start college, and I'm like how am I going to let her go someplace else? We're like joined at the hip. We're about as close as a mother and daughter could possibly be. I mean besides being my daughter, she is also a very close friend.

This mother expresses her worries about the future as well:

She wants to be a doctor. And she's got the smarts to do it, but she wants to go away to college. [I said to her], ' It's going to be an overwhelming experience for you to go to college. First of all you've got to manage all

your medical stuff and your illness and your supplies and all that, plus study and be social. How are you going to do all that? Why don't you live at home for maybe the first year and you be responsible and I'll be there as a back-up.' You're like trying to balance this crazy illness with its highs and lows, and plan for the future all along with that.

Most of these mothers knew only too well how tenuous the lives of their children were. If they themselves had not experienced near death encounters with their own child they had certainly been exposed to children of other parents dying when their own child was hospitalized. Uppermost in their minds when this happened was the question, 'Is my child next?' as this mother relates:

Children have always died. But when you are in a normal environment and normal community, you may only know one or two your entire life. But when you're in a hospital setting, where you meet more and more people that have special needs children, probably the last three years I've known 20 children who have died, and their parents. And so I'm in a whole new community world now. Things I never thought I would see. So it has changed my perspective on a lot of things in life. ...But for so many parents when you hear someone's kid has died, you think is that us next? Are we going to have a funeral in this church next? Are we going to...? Is that us... next? It scares the daylight out of you.

In other instances, friendships had been formed with other families with a child with a similar or identical diagnosis, who subsequently died. As this mother describes:

I saw kids die when they were three, four. We went to funerals of kids that were on TPN. Most of them did die by the time they were five unless they were off. And then we had a little girl that we got really close to. She had an intestinal transplant and she died four years ago this month. And when she died that was the hardest. Cause we were really close to that kid. And when she died, that was really hard for all of us... I always say we had the death and dying talk with her more so than the sex talk. We would tell her that hopefully you'll be here for a long time, but we don't know what's going to happen with you. We try and be honest with her.

Many of them had been confronted with the question of death from their own child as this mother explains:

In fact, he has even asked this. Am I going to die from this? That's a heart-breaking thing to answer. We've told him (his brother) could walk out tomorrow and walk into the middle of the street and get hit by a car. We don't know when any of you guys are going to die We don't want any of you guys to die. This is hard on your body, but look at how well you're doing.

Others had actively planned funerals with the child as this mother explains, " We were just real straightforward and we told him and he planned his funeral, and we went and picked out a plot and bought a plot, and found out the laws."

Most mothers despite being realistic about the possibility of an early death for their child also held out hope for medical advancements that might prolong their child's life as this mother explains:

We've mentioned that we know that we will probably outlive her. But we also are aware of different advancements that are happening around the world, such as tissue engineering. And I know right now that they are successfully growing bladders and implanting them in the kids, engineering their own tissues, and our hope and this is ... this is our hope.

This category then is characterized by a realization of the lost opportunities and concurrent emotions in this intense care. To counteract these feelings, respite and support are sought out and embraced. Finally the future is contemplated to put life in perspective. The final category examines the positive consequences of this care.

### *Celebrating the Positive*

The successful protective care these mothers employed led to a celebration of the positive aspects of each child and his care. They had 'discovered the silver lining' or 'blessings' as many of them phrased it to watching over this child. Additionally they derived pride and satisfaction from the mothering experience of protecting this child from harm and

keeping this child alive. These mothers all had positive comments to make about the experience of having a child like this in their lives despite "all the extra care, the extra cost, the extra stress." These comments ranged from the "blessing" in her life, the "gift", to how "lucky they were to have him." Many of the comments centered on the compassion the child had created among family members for other people, how the child had brought the parents closer together or to the fact that this child had helped them determine what was most important in their lives. This mother may have captured a composite of some of the feelings:

I'd give anything in the world to change it and have a normal life, but we live our life a lot more fully because of what we've been through. We appreciate things in which there's no way I would appreciate in my age and stage of life right now; that I wouldn't have this perspective if we didn't have this with him. And he is the reward. Having every moment I have with him. I would just take everything for granted, and I'm still young, the kid's young, we've got forever. But every day and every little thing they do, we stop and appreciate. Our time together is much more rewarding now and we've got the big picture because of it.

A definite feeling that emerges from most of these mothers is pride in their successes. This is evident when they discuss or "brag" about keeping the child from sepsis, or how their child has "beaten the odds" and escaped a death that had been predicted much earlier in life. This mother expresses the concept of "beating the odds" this way:

She is slender for her age. She is at the very bottom of the growth curve but for her to get to that point even is amazing. She wasn't supposed to live to be a year old. And then it was three, then it was five, then it was eight, now it's 15.

Another mother describes the negative feedback regarding her daughter's future; she received from a health care professional when inquiring about the child's care this way:

I said (to the nurse) 'what do I do, when she starts crawling and she's on this TPN?' and... She said, 'honey she won't crawl. She'll never make it. She's too sick, and you're too young to take care of her.' I saw that nurse just recently. And I kept walking. I mean it was just wonderful.

These mothers also derived tremendous satisfaction from keeping their child free from sepsis or line infections. Most could relate exactly how many years or months they had gone without an infection or the exact number of lines which had been placed during their care. These moms express this, "And we went a year with the central line with no infections", and "Up until now, he's only had one septic episode which he had last week", and "I've kept one catheter in for two and a half years."

. She also expresses satisfaction when this child is accepted by his peers and from "seeing him grow" despite his inability to eat normally. Observing her child take pleasure from life despite this disability is also pleasurable as this mother describes:

Seeing him smile and laugh when he is feeling good and knowing then that I'm doing a good job. That's got to be the ultimate. When he is feeling good and when he's got this laugh and this smile that never ends that is totally contagious, I know that I've done okay. And he walks up and goes, 'you're my bestest mom.' (Laugh) I have to remind him that 'I'm your only mom.' But just... having him tell that... myself... is just knowing that this is worth it, because look at how happy he is now and how good he is feeling.

In summary, in this category, these moms celebrate the positive by discovering the 'silver lining' or sometimes hidden benefits of mothering this child, that may only emerge in retrospect. Pride and satisfaction are the celebration of their perseverance and the result of their real success in providing protective care.

This chapter has presented the theory of Protective Care grounded in the words of the mothers interviewed. Categories have been derived from the data which serve to

depict the role of mothering a child dependent on parenteral nutrition. These categories described the antecedents, strategies and consequences of this protective role.



## CHAPTER V

### DISCUSSION OF FINDINGS

This chapter discusses the overall theory in comparison to similar theories and then explores each of the categories individually in the context of existing literature. The interrelationships within the categories will also be identified and discussed.

#### The Grounded Theory of Protective Care

Protective Care, the overriding basic social process identified in this study broadly describes the mothering experience for children dependent on parenteral nutrition. The protective care pervades all of her actions with the child, the health care system and the community at large. Although the resulting theory is categorized, the actual process is highly integrated and interdependent.

The concept of protective care may parallel the mothering concept identified by Ruddick (1995) as 'preservation of life.' Ruddick's explanation of this imperative takes into account most mothers' responses to their helpless infant who "demand" preservative care. Ruddick's theory proposes that this protective mode is rapidly supplanted by what she terms the second demand, nurturing emotional and social growth of this child. Here the comparison diverges as these mothers although most certainly concerned with emotional and social growth as well as Ruddick's third stage of acceptability, must maintain their fierce protective care to preserve this child's life for the duration of the dependence on parenteral nutrition. The preservative care or protective care of these

children involves a more intense vigilance than that of a child who is not dependent on this type of technology. The mothers in this study are essentially carrying out activities each day, which performed improperly, could quickly result in the child's demise. Their level of protective care is mediated at times, but never discounted as an essential task that permeates the lives of these mothers.

### *Gaining Control*

The antecedent to Protective Care was subsumed in the category of Gaining Control. This category embodied all of the preparatory work to begin the protective care of mothering this child. These mothers were anxious to exercise control over the life of their child. To do so, they wanted to wrest them away from the hospital, get them home and begin to make sense of the situation.

The commitment to care, identified as integral to beginning that process is similar to one of the behavioral responses mothers' display to diagnosis of a chronic illness in their child, that Gibson (1995) discusses in her theory development of empowerment in mothers of chronically ill children. Assuming responsibility, as in the current study, was the only option the mothers saw and there were no other choices.

Preparing to take the child home is of high priority to these mothers as in McKeever's (1992) research and they try to absorb as much instruction as possible in order to get their child home. Many of the mothers spend long hours, days, nights and weeks in the hospital becoming familiar with all of the equipment and care their child needs.

Upon arriving home with the child, these mothers experienced a myriad of emotions similar to Gibson's (1995) description of the first phase of discovering reality, in her study of the process of empowerment in mothers of chronically ill children. The emotional responses she describes include; bewilderment, shock, confusion, fright, anxiousness and anger. Most of these emotions are mirrored in the current study. The feeling of fear so prevalent in the current study is also described in McKeever's (1992) research.

Her ability to organize the myriad tasks with which she is faced contributes to her sense of self esteem and is a source of satisfaction (Pridham, Lin, & Brown, 2001). Wilson and Morse (1998) also acknowledge the construction of routines and schedules as a source of security to the mother.

### Watching Over

The importance of unremitting but shifting vigilance levels has been noted in much of the previous research not only in technology dependent children but with other chronic illnesses as well (McKeever, 1992; O'Brien, 2001; Stewart & Mishel, 2000; Wilson & Morse, 1998). This vigilance concept permeates the life of these mothers and essentially governs all of their activity.

As these mothers care for this child dependent on parenteral nutrition, they progress from naiveté to knowledgeable expertise. The knowledge-experience base builds up over time and enables them to hold their own with professionals. These women came to know their children in the intuitive way described by Belenky, Clinchy, Goldberger and Tarule (1986) as one of women's ways of knowing which is subjective, "an inner

voice" deriving from experience. This knowing empowered them to move from the role of received knowledge to one of self-assertion, which served to protect their children. They gained confidence in their knowledge through experience for caring for their child and voiced their concerns with the health care team when they perceived inequities. They did not want to assume "powerless responsibility" (Rich, 1986).

In all of these instances of mothering, the child "showed up as a person" as described by Leonard (1996, p. 127), not as "an object." In Leonard's discussion of mothering, she explains the concept of mothering as a practice rather than a technique. If mothering were a collection of techniques, she maintains, the mother would not need to have or expect a relationship with the child. Rather when the concept of practice is evoked, there is a definite relationship with the child as a person who has needs with developing abilities. All of the mothers in this study embodied that concept and showed an intuitive understanding of those needs, which they staunchly defended.

The role conflict, which results from the mothering versus nursing role, was well articulated by many mothers and finds a corollary in the work of Wilson and Morse (1998). These researchers report that "having to induce suffering, for example to "beat on" a child undergoing chest percussion... was contrary to the affection they wanted to convey as a mum" (p. 230). Some mothers during periods of technical care were forced to separate themselves and care *for* rather than *about* the child.

### Challenging the System

Gibson's (1995) description of the process of empowerment in mothers of chronically ill children parallels the current study. This category mirrors her category of

"taking charge." As in her study, taking charge resulted in advocacy for the child using negotiating skills and persistence to get what they needed from health professionals, reimbursement systems, and the schools. This form of advocacy is expressed in Thorne and Robinson's (1989) concept of "guarded alliance" as consumerism. The express purpose of interaction was to obtain essential services for the child.

Despite studies showing that most parents of chronically ill children want a partnership with health professionals, this partnership is rarely achieved according to Fisher (2001). The results of the current study bear no exception. Very few of these mothers appeared to have a smooth alliance with medical and nursing professionals and didn't demonstrate the "guarded alliance" described by Thorne and Robinson (1989), characterized by trust reconstructed after the previous stages of "naïve trust" and "disenchantment." The mothers continually fought to gain control over the care of their child, spending a significant amount of time doing so.

These mothers showed great reluctance to relinquish care of their child to anyone else. This was particularly true of hospitalizations where they had observed errors, breaks in techniques and other mistakes made by the nursing and physician staff. As a result, they never left the hospitalized child and were most vigilant in observing all care administered to their child and often preferred to do it themselves. Parents' distress related to hospitalization of a child with a chronic condition has been documented in the literature (Balling & McCubbin, 2001; Burke, Kauffman, Costello, & Dillon, 1991). Burke and others discuss this process and label this as a subset of Reluctantly Taking Charge - vigilance and taking over. In their grounded theory, parents of chronically ill

children develop a set of behaviors to cope with repeated hospitalizations of their child. It begins with parents' observations of omissions and errors in care, negative information and observing novice health care workers who are essentially practicing their care with these children when the child is hospitalized. If those behaviors are not changed by the health care workers with polite requests, parents resort to taking over by maintaining constant vigilant behavior, negotiating rules and tenacious information seeking. With a prolonged hospitalization, this vigilance may take its toll with exhaustion. In the current study, this also resulted in guilt for many of these mothers who felt they were not able to adequately care for the technology dependent child's siblings at home.

Balling and McCubbin (2001) in a more recent study found similar reactions of parents to repeated hospitalizations of their chronically ill child. In their content analysis of open-ended questions to 50 parents, they found, among other findings, that parents felt their care of the child was better in the home than the hospital, a finding which is clearly reflected in this current study.

Nursing care in the home was also a source of consternation for the mothers in the current study. They describe great difficulty in finding someone who was knowledgeable and who cared about their child. When they did find someone who fit that description, they held on to them tenaciously for as long as possible realizing how valuable this person was to them. Occasionally they even found their own person, who might not be an RN, but who was trained to their standards, and once trust had been established allowed them to perform skills which legally were out of their scope of practice. Coffman's (1995) study of pediatric nurses in the home concurs with these observations of mother's

relationships with nurses from various agencies. Finding the right nurse who could blend in by sharing some of the same belief systems of the parents and who could be flexible in their care was important to them.

### Promoting Normalcy

The quest of most parents to promote normalcy for children with chronic illness has been well documented in the literature (Fisher, 2001; Knafl & Deatrck, 2002). The current study serves to illuminate the struggle to put some normalizing features into the life of the child with a dependence on technology. As was illustrated in the responses from these mothers, their lives may appear abnormal to most, but to them the abnormal becomes normal. While this may be a bit more difficult with a child who is so completely dependent on technology compared to a child suffering from other chronic illnesses such as asthma or diabetes, most of the principles are the same. These mothers become haunted by guilt if they do not engage in the protective care, but at the same time must try to equalize the protection with some semblance of a normal life.

Uncertainty, the persistent factor pervading all lives of mothers' who have a chronically ill child (Stewart & Mishel, 2000) is quite visible in the current study. The challenge to provide some semblance of a normal life despite the uncertainty is verbalized by these mothers. They appear to have the ability to move beyond the uncertainty and accept it as a way of life, using the information seeking style of questioning and vigilance identified by Stewart and Mishel to successfully manage those feelings

Though little attention on normalcy issues in regard to feeding and eating in this specific population is found in the literature, feeding and caring are intertwined (DeVault, 1991; Pridham, Schroeder & Brown, 1999). One of the salient roles of a mother is to feed her child. Feeding an infant is an important means of attachment in the newborn period. When that role was disrupted, the mothers in this study described feelings of helplessness and frustration. If their child subsequently became able to eat normally, they felt tremendous gratification and satisfaction from feeding the child and watching the child eat.

If successful feeding is accompanied by a feeling of competence in the mothering role (Pridham, Lin, & Brown, 2001; Rubin, 1984), it might be surmised that the mother who is unable to feed her child would suffer from loss of self-esteem and self-confidence. The mothers in this study did not, most likely because their self-esteem and self-confidence could be bolstered by their ability to provide the complicated care that accompanied this child's dependency on technology. They did however experience emotions of sadness, frustration and guilt related to feeding issues. They also clearly missed the opportunity to feed their child, particularly when the child was an infant.

According to these mothers, attachment between mother and child was still accomplished, although traditional feeding did not take place. They seemed to attribute this to the intense care they performed with this child which provided the closeness needed for attachment to occur. They did however admit that the initial attachment might take longer, but then observed, it also might be stronger than in a normal mother-infant dyad.



### Putting Life in Perspective

In this category we see most of these mothers finding some way to make sense of the situation in which they find themselves. They have found ways to adapt to a seemingly unbearable situation by recognizing lost dreams and opportunities, acknowledging the emotions of anger and guilt, finding respite and support and then contemplating the future. The ability to cope with the stress of caring for a chronically ill technology dependent child has been documented but not fully explained in the literature. This ability may relate to individual maternal temperament as suggested by Affleck and Tennen (1993). They relate a transition from 'victims' to 'survivors' point of view as a phenomenon which still needs exploration, but may indeed be interrelated to the amount of control perceived in a given situation.

### Celebrating the Positive

These mothers found positive elements of their life despite the hardships. Affleck and Tennen (1993) found similar responses in adapting to adversity in parents of medically fragile infants diagnosed at birth. They emphasize the tremendous resiliency people demonstrate in the aftermath of a traumatic event. Although none of these mothers articulated the subcategory of "finding a purpose" under these researcher's overall category of "Finding Meaning", they did appear to "construe benefits" and "make comforting comparisons." As described in the study, these mothers found positive characteristics of their child and the effect caring for that child has had on them and their family in general. Their sense of confidence and self-worth is greatly enhanced by a successful caregiving experience.

In summary, the similarities of previous studies related to the care of chronically ill children serve to validate the present study. Commonalties among the experience of mothers of chronically ill, medically fragile and /or technology dependent children would be expected among these mothers of children dependent on parenteral nutrition. This discussion of the findings has presented the shared discoveries and contrasted these with the unique experiences of the mother of a child dependent on parenteral nutrition to provide a cohesive theory of that mothering role.

## CHAPTER VI

### IMPLICATIONS AND RECOMMENDATIONS

The continuing use of high technology to intervene into the lives of critically and chronically ill children accompanied by the increasing costs for hospital care and the imperative that these children be cared for at home has resulted in increasing numbers of technology dependent children at home. Here the child's mother most often assumes responsibility for the care this child needs and alters her life to accommodate this intense mothering role. This study has formulated a grounded theory of Protective Care, reflecting the experience of mothering a child dependent on parenteral nutrition. This chapter provides a discussion of the critique of this study and then offers implications and recommendations for health policy, nursing practice, education and research.

#### Critique of the Study

Strengths of the study include the wide geographic area of the sample, the diversity in ages of the mothers and their children, the range of educational backgrounds of the mothers, and the range of diagnoses which led to dependence on parenteral nutrition. This wide range of diversity in the mothers interviewed serves to enhance the validity of the resulting theory.

Furthermore adherence to methodology to establish trustworthiness, the hallmark of sound grounded theory constitutes another strength of the study. This includes the establishment of credibility, transferability, dependability, and confirmability.

Credibility was established by spending time with the informants, using reflexive analysis, keeping a field journal, using member checking and peer examination, as well as employing consistent interviewing techniques. Peer examination of the data also helped to achieve dependability and peer debriefing or discussion of the data with the same two peers helped establish trustworthiness. Transferability was enhanced by providing dense background information to allow others to make suitable comparisons.

Limitations might include the predominance of Caucasians as the participants and the fact that all mothers volunteered to be interviewed. Socioeconomic background was not elicited as a demographic piece from these mothers and may have also shown a similar range.

### Implications and Recommendations

Implications and recommendations are indicated in three areas. These include changes in health policy, nursing practice and recommendations for further research.

#### *Health Policy*

In our increasingly technological world, policy makers must recognize the implications of employing technology with chronically and acutely ill children as costly to families who must provide the care. Many of the mothers in this study had suffered financial losses; two of them had lost homes as the result of the out-of-pocket expenses incurred in their child's care. As was discussed, most of these mothers spent a good share of their time struggling with payors for basic supplies and respite care. Future goals would include the provision of financial support for each child's care before discharge with periodic examination of the financial state of the household. If the technology of

parenteral nutrition is to be instituted, health policy should dictate sufficient reimbursement for families expected to care for these children. An interdisciplinary effort between health care policy-making and service delivery is essential (Cross, Leonard, Skay & Rheinberger, 1998).

Managed care issues must be taken into consideration with realization that the cost of out-of-pocket spending is high. Case management may be needed to help individual mothers coordinate and manage the myriad of health care providers, pharmaceutical supplies, equipment vendors and home health agencies. Funding for these essential services should be provided which is easily procured without an intense time commitment.

Finally, institution of this technology must be continually weighed with the emotional and financial costs incurred as a result of this therapy. Statistics need to be kept regarding numbers of children dependent on parenteral nutrition and other forms of technology so the emotional, social and financial costs of this technology may become known.

### *Nursing Practice*

If the mother is a "subjective knower", the health care team should learn to be "connected knowers" when interacting with the mothers of these children. According to Belenky et al. (1986), the connected knower "develops procedures for gaining access to other people's knowledge." Having gained that knowledge the other becomes connected through empathy and begins to understand the experience through the eyes of that person. The purpose is not to judge in this instance, but to understand what each mother is going

through and her perspective of her child, what works for her. Too often, according to these mothers, their knowledge is not valued or even heard amid the rhetoric of research and textbook approaches to medical care.

As Burke et al. (1991) state in their research of the stress incurred by parents of chronically ill children with repeated hospitalizations, many health care professionals do not see themselves as part of the problem whereas in the current study as well as others, the health care professionals are clearly much of the problem perceived by these mothers. The current lip service being paid to "evidence-based practice" and "family centered care" does not seem to be practiced with consistency.

The value of preparatory teaching for this population is documented in the literature (Bendorf & Lyman, 1993) but examination of the results of that teaching has not been addressed. The mothers in the current study felt for the most part that the teaching was inadequate and did not prepare them for any of the emotional strain they would experience. Assessment guides such as the one developed by Melynk, Feinstein, Moldenhauer and Small (2001) should be employed to ascertain mothers' views of their own situation "without making assumptions about their stressors and needs" (p. 554). Once the situation has been assessed, specific interventions can be made.

Emotional care must also be provided for these mothers who take on this tremendous task. Many of these mothers at least initially were unaware of other situations similar to their own and had to discover support systems independently.

Effective case management of these families would appear to be a reasonable solution to many of the issues these mothers have regarding coordinating services,

reimbursement, utilizing resources, and negotiations with schools and other health care providers. Efforts could be made to alleviate some of the time and energy these mothers spend with agencies, service providers and the health care system to relieve the burden of constant advocacy for their child.

Specific recommendations would be to teach another family member the care of each child discharged on parenteral nutrition, not expecting the mother to be the sole source of knowledge regarding care.

The transition from hospital to home must be made smoother, with home health professionals familiar with the intricacies of care of these children and their equipment, readily available at discharge to smooth the path in the first few weeks of care at home.

#### *Nursing Education*

The education of the nurse both at the graduate and undergraduate level must include content related to assessment and intervention skills to enable the practitioner to evaluate the effect of mothering a technologically dependent child. As appropriate interventions to strengthen that caregiving role are identified, these must be implemented and then evaluated appropriately.

Using information gleaned from this study, the intense mothering role of a child dependent on parenteral nutrition, is similar to mothering a child with other technologies, but unique in the feeding difficulties and various eating behaviors observed. The unique needs of this population needs to be recognized and communicated to all students.

The nurse at the bedside must be made aware of the skill set these mothers have developed and respect the knowledge and intuition each mother brings with her child

upon recurring admissions to the hospital. Recognition of the skill sets will enable further partnering with each mother for improved care of the child.

### *Research*

The experience of mothering a child who is experiencing feeding problems and eating disorders remains intriguing and a fertile area for further research. Although examined in the current study, other topics for further research might include children dependent on alternative forms of nutrition other than normal oral feedings. The effect of these forms of feeding among age groups could be identified so as to determine the best interventions for mothers of children of varying ages.

Culturally diverse ethnic groups need to be approached and included in another similar study. The mothering styles of other ethnic groups may reflect differing viewpoints on the same issues discovered in the current study or other issues may emerge in their mothering experiences.

Upon completion of a qualitative study such as this one, instrument construction could now be proposed and tested to measure the emergent theory's concepts. Once those are established as reliable indicators, many other quantitative studies could be devised to sample the population with intervention studies as an ultimate goal.

All of these mothers volunteered to be interviewed. It might be argued that perhaps the women, who did not volunteer, might be the ones from whom we would like to hear. The voice of the mothers who were not able to meet the challenge of caring for this technology dependent child at home needs to be contrasted with these seemingly successful mothers. Increasingly mothers decide they are unwilling to take on this life-



consuming task or may begin the care, but are found to be neglectful or abusive and their child is removed from their home and placed in foster care. There is a need to discover the experience of these mothers, not for the purpose of placing blame, but to determine when it might not be in the best interest of the mother or child to promote this caregiving relationship. Intervention studies using information obtained from this and other qualitative research need to be planned to determine effective means for evidence-based interventions.

In summary, indications for changes in health policy, nursing education, practice and further research have been discussed. Health policy must be changed to reflect the needs of these mothers if they are expected to care for these technology dependent children at home. This includes, but is not limited, to appropriate funding for all costs incurred in the care of these children, with sufficient reimbursement easily obtained for all equipment, drugs and home health support, including the services of a case manager. Nursing education and practice must recognize the learning needs of these mothers before discharge, their emotional states upon the commencement of care, and then acknowledge the expertise these mothers develop over time. Finally research possibilities include interviewing mothers of other cultural backgrounds, mothers who opted not to undertake this experience or who were deemed unsuited to continue in the mothering role. The development of quantitative tools with subsequent intervention studies present further options.

## Conclusion

In this age of increasing reliance on technology, it is important to continually reassess the impact of the means we have devised to prolong life. Although quality of life is a highly subjective concept, indicators of suffering both in the lives of the children dependent on the technology and their primary caregiver, the child's mother must be appraised.

The mothers who were interviewed for this study might be characterized as "successful" mothers. They are performing the tasks of raising this child well enough that the child has not died or needed to be removed from the home. They have not suffered mental breakdowns or physical illness as the result of this intense care severe enough to prevent them from continuing in the role. Their strengths and abilities may serve as indicators of the ingredients needed for successful mothering of a child dependent on parenteral nutrition.

## REFERENCES

- Affleck, G., & Tennen, H. (1993). Cognitive adaptation to adversity: Insights from parents of medically fragile infants. In A.P. Turnbull, J. M. Patterson, S. K. Behr, J. G. Marquis, & M. J. Blue-Banning (Eds). *Cognitive coping: Families and disability* (pp.136-149). Baltimore: Paul H. Brooks.
- Ainsworth, M. D. (1967). *Infancy in Uganda*. Baltimore: Johns Hopkins Press.
- Ament, M. E. (1995). Home total parenteral nutrition In C.C. Roy, A. Sullivan, & D. Alagille (Eds.). *Pediatric Clinical Gastroenterology* (pp.1666-1688). St. Louis: Mosby.
- Anderson, D. G., & Hatton, D.C. (2000). Accessing vulnerable populations for research. *Western Journal of Nursing Research*, 22 (2), 244-251.
- Anderson, J. A., & Elfert, H. (1989). Managing chronic illness in the family: Women as caretakers. *Journal of Advanced Nursing*, 14, 735-743.
- Anderson, J. A. (1990). Home care management in chronic illness and the self-care movement: An analysis of ideologies and economic processes influencing policy decisions. *Advances in Nursing Science*, 12, 71-83.
- Andrews, M. M., & Nielson, D. W. (1988). Technology dependent children in the home. *Pediatric Nursing*, 14, 111-114.
- Anspach, R. R. (1993). *Deciding who lives: Fateful choices in the intensive-care nursery*. Berkeley: University of California Press.

- Apple, R. D. (1987). *Mothers and Medicine: A Social History of Infant Feeding 1890-1950*. Madison: The University of Wisconsin Press.
- Arras, J. D., & Dubler, N. N. (1995). Ethical and social implication of high-tech home care. In J. D. Arras, H. W. Porterfield, & L. D. Porterfield (Eds.), *Bringing the hospital home: Ethical and social implications of high-tech home care*. (pp. 1-31). Baltimore: Johns Hopkins Press.
- Baker, J. P. (1996). *The machine in the nursery: Incubator technology and the origins of infant intensive care*. Baltimore: The Johns Hopkins University Press.
- Baker, J. P. (2000). The incubator and the medical discovery of the premature infant. *Journal of Perinatology*, 5, 321-328.
- Balling, K., & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing*, 16 (2), 110-119.
- Barnard, K. (1978). *The nursing child assessment feeding scale*. Seattle, Washington: University of Washington Press.
- Barnett, C. R., Leiderman, P. H., Grobstein, R., & Klaus, M.H. (1970). Neonatal separation: The maternal side of interactional deprivation. *Pediatrics*, 45, 197-205.
- Basin, D., Honey, M., & Kaplan, M. M. (1994). *Representations of motherhood*. New Haven: Yale University Press.
- Belenky, M. F., Clinchy, B. M., Goldberger, N. R., & Tarule, J. M. (1986). *Women's ways of knowing: The development of self, voice and mind*. Basic Books.

- Bendorf, K., & Lyman, B. (1993). Transition from the hospital to the home for the infant requiring total parenteral nutrition. *Journal of Perinatal Neonatal Nursing*, 6 (4), 80-90.
- Betschart, J. (1987). Parents' understanding of and guilt over their children's blood glucose control. *Diabetes Educator*, 13, 398-401.
- Billings, J. R. (1995). Bonding theory—tying mothers in knots? A critical review of the application of a theory to nursing. *Journal of Clinical Nursing*, 4, 207-211.
- Binstock, R.H., & Cluff, L. E. (2000). Issues and challenges in home care. In R. H. Binstock & L. E. Cluff (Eds.) *Home care advances: Essential research and policy issues* (pp. 3-24). New York: Springer.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, N.J.: Prentice-Hall.
- Boland, S. L., & Sims, D. L. (1996). Family caregiving as a solitary journey. *IMAGE*, 28 (1), 55-58.
- Bowlby, J. (1965). *Child care and the growth of love*. Baltimore: Penquin Books.
- Brimblecombe, F. S. W. (1983) Evolution of special baby care units. In J. A. Davis, M. P. M. Richards, & N. R. C. Robertson (Eds.), *Parent-baby attachment in premature infants*. (pp. ) New York: St. Martin's Press.
- Brooten, D., Kumar, S., Brown, L. P., Butts, P., Finkler, S. A., Blakewell-Sachs, S., Gibbons, A., & Delivoria-Papadopoulos, M. (1986) . A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. *New England Journal of Medicine*, 315, 934-939.

- Brunier, G. M., & McKeever, P. T. (1993) The impact of home dialysis on the family: Literature review. *ANNA Journal*, 20, 653-659.
- Burke, S. O., Harrison, M. B., Kauffmann, E., & Wong, C. (2001). Effects of stress-point intervention with families of repeatedly hospitalized children. *Journal of Family Nursing*, 7 (2), 128-158.
- Burke, S. O., Kauffmann, E., Costello, E., & Dillon, M. (1991). Hazardous secrets and reluctantly taking charge: Parenting a child with repeated hospitalizations. *IMAGE*, 23 (1), 39-45.
- Burke, S. O., Kauffmann, E., Costello, E., Wiskin, N., & Harrison, M. B. (1998). Stressors in families with a child with a chronic condition: An analysis of qualitative studies and a framework. *Canadian Journal of Nursing Research*, 30 (1), 71-95.
- Burr, B. H., Guyer, B., Todres, I. D., Abrahams, B., & Chiodo, T. (1983). Home care for children on respirators. *New England Journal of Medicine*, 309, 1319-1323.
- Byers, J. E., & Fabian, A. M. (1988). The parent drop-out syndrome. *Caring*, 7, 5-7.
- Cain, L. P., Kelly, D. H., & Shannon, D. C. (1980) Parents' perceptions of the psychological and social impact of home monitoring. *Pediatrics*, 66, 37-41.
- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science Medicine*, 30, (11), 1161-1172.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2<sup>nd</sup> ed). (pp. 509-535). Thousand Oaks, CA: Sage Publications.

- Cluff, L. E., & Brennan, P.F. (2000). The use of technology in home care. In R. H. Binstock & L.E. Cluff (Eds.), *Home care advances: essential research and policy issues* (pp. 59-77). New York: Springer.
- Coffman, S. (1995). Crossing lines: Parents' experiences with pediatric nurses in the home. *Rehabilitation Nursing Research*, 4 (4), 136-143.
- Cohen, M. H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research*, 5 (1), 63-77.
- Coll, C. C., Surrey, J. L., & Weingarten, K. (1998). *Mothering against the odds*. New York: Guilford Press.
- Conrad, P. (1988). Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science and Medicine*, 30, 1257-1263.
- Cross, D., Leonard, B. J., Skay, C. L., & Rheinberger, M. M. (1998). Extended hospitalization of medically stable children dependent on technology: Focus on mutable family factors. *Issues in Comprehensive Pediatric Nursing*, 21, 63-84.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31 (6), 1476-1484.
- Damato, E. G. (1991). Discharge planning from the neonatal intensive care unit. *Journal of Perinatal and Neonatal Nursing*, 5, 43-53.
- DeVault, M. L. (1991). *Feeding the family: The social organization of caring as gendered work*. Chicago: The University of Chicago Press.
- Devettere, R. J. (2000). *Practical decision making in health care ethics*. (2<sup>nd</sup> ed.). Washington, D.C.: Georgetown University Press.

- Dixon, D. M. (1996). Unifying concepts in parents' experiences with health care providers. *Journal of Family Nursing*, 2 (2), 111-132.
- Dodgson, J. E., Garwick, A., Blozis, S. A., Patterson, J. M., Bennett, F. C. & Blum, R. W. (2000). Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*, 6 (3), 252-266.
- Donar, M. E. (1988). Community care: Pediatric home mechanical ventilation. *Holistic Nursing Practice*, 2, 68-80.
- Feinberg, E. A. (1985). Family stress in pediatric home care. *Caring*, 38-40.
- Feinberg, E. A. (1991). Ethical issues. In M. J. Mehlman & S. J. Youngner (Eds.), *Delivering high technology home care*. (pp. 84-124). New York: Springer.
- Fisher, H. R. (2001). The needs of parents with chronically sick children: A literature review. *Journal of Advanced Nursing*, 36 (4), 600-607.
- Frates, R. C., Spalingard, M. L., Smith, E. D., & Harrison, G. M. (1985). Outcome of home mechanical ventilation in children. *Journal of Pediatrics*, 106, 850-856.
- Galea, M. H., Holliday, H., Carachi, R., & Kaplia, L. (1992). Short bowel syndrome: collective review. *Journal of Pediatric Surgery*, 27 (5), 592-596.
- Gibson, C. H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 21, 1201-1210.
- Gilligan, C. (1982). *In a different voice*. Cambridge, Massachusetts: Harvard University Press.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.



- Glenn, E. N. (1994). Social constructions of mothering: A thematic overview. In E. N. Glenn, G. Chang, & L. R. Forcey (Eds), *Mothering: Ideology, experience and agency* (pp.1-29). New York: Routledge.
- Guyer, B., Hoyert, D. L., Martin, J. A., Ventura, S. J., MacDorman, M. F., & Strobino, D. M. (1999). Annual summary of vital statistics – 1998. *Pediatrics*, 104 (6), 1229-1246.
- Haas, J. S., & McCormick, M.C. (1997). Hospital use and health status of women during the 5 years following the birth of a premature, low-birthweight infant. *American Journal of Public Health*, 87 (7), 1151-1155.
- Handy, C. J. (1988). Home care of patients with technically complex nursing needs. *Nursing Clinics of North America*, 23 (2), 315-328.
- Hazlett, D. (1989). A study of pediatric home ventilator management: Medical, psychosocial, and financial aspects. *Journal of Pediatric Nursing*, 4 (4), 284-294.
- Hoffman, R.L., & Mitchell, A. M. (1998). Caregiver burden: Historical development. *Nursing Forum*, 33 (4), 5-11.
- Hogue, E. (1992). Parental noncompliance in home care. *Pediatric Nursing*, 18, 603-606.
- Holditch-Davis, D., Miles, M. S., & Belyea, M. (2000). Feeding and nonfeeding interactions of mothers and prematures. *Western Journal of Nursing Research*, 22 (3), 320-334.
- Howard, L., Ament, C., Fleming, C. R., Shike, M., & Steiger, E. (1995). Current use and clinical outcome of home parenteral and enteral nutrition therapies in the United States. *Gastroenterology*, 109 (2), 355-365.

- Humphrey, R. (1991). Impact of feeding problems on the parent-infant relationship. *Infants and Young Children*, 3 (3), 30-38.
- Jackson, P. (2000) The primary care provider and children with chronic conditions. In P.L. Jackson & J. A. Vessey (Eds.), *Primary care of the child with a chronic condition*. (pp. 3-19). St. Louis: Mosby.
- Jakubik, L. D., Colfer, A., & Grossman, M. B. (2000). Pediatric short bowel syndrome: Pathophysiology, nursing care, and management issues. *Journal of the Society of Pediatric Nurses*, 5 (3), 111-121.
- Kang, R., Barnard, K., Hammond, M., Oshio, S., Spencer, C., Thibodeaux, B. & Williams, J. (1995). Preterm infant follow-up project: a multi-site field experiment of hospital and home intervention programs for mothers and preterm infants. *Public Health Nursing*, 12 (3), 171-180.
- Katz, K. S., Baker, C., & Osborn, D. (1991). Home-based care for children with chronic illness. *The Journal of Perinatal and Neonatal Nursing*, 5 (1), 71-79.
- Klaus, M., & Kennell, J. H. (1976). *Maternal-infant bonding*. St. Louis: Mosby
- Knafl, K. A., & Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing*, 28 (1), 49-53, 56.
- Kohrman, A. F. (1991). Psychological issues. In M. J. Mehlman & S. J. Youngner (Eds.), *Delivering high technology home care*. (pp. 160-178). New York: Springer.
- Krajewski, D. M. (1990). Helping families cope with the chronically ill child at home. *Journal of Home Health Care*, 3 (2), 39-46.

- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45 (3), 214-222.
- Ladd, A. P., Rescorla, F. J., West, K. W., Scherer, L. R., Engum, S. A., & Grosfield, J. L. (1998). Long-term follow-up after bowel resection for necrotizing enterocolitis: Factors affecting outcome. *Journal of Pediatric Surgery*, 33 (7), 967-972.
- Leonard, B. J., Brust, J. D., & Nelson, R. P. (1993). Parental distress: Caring for medically fragile children at home. *Journal of Pediatric Nursing*, 8, 22-29.
- Leonard, V. W. (1996). Mothering as a Practice. In S. Gordon, P. Benner, & N. Noddings (Eds.), *Caregiving: Readings in Knowledge, Practice, Ethics, and Politics* (pp. 124-140). Philadelphia: University of Pennsylvania Press.
- Levitsky, S., & Cooper, R. (2000). Infant colic syndrome - Maternal fantasies of aggression and infanticide. *Clinical Pediatrics*, July, 395-402.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park CA: Sage.
- Lubkin, I., & Payne, M. E. (1995). Family caregivers. In I. M. Lubkin (Ed.), *Chronic illness, impact and intervention*. (pp. 261-284). Boston: Jones & Bartlett.
- Lynch, M. (1990). Home care of the ventilator-dependent child. *Children's Health Care*, 19 (3), 169-173.
- McKeever, P. T. (1992a). *Mothering chronically ill, technology dependent children: An analysis using critical theory*. Unpublished doctoral dissertation, York University, North York, Ontario.

- McKeever, P. T. (1992b). Mothering children who have severe chronic illness. In A. Ambert (Ed.), *The effect of children on parents*. (pp. 170-190). New York: Haworth Press.
- McNeil, B. J., & Cravalho, E. G. (1982). *Critical issues in medical technology*. Boston: Auburn.
- Malloy, C., & Hartshorn, J. (1989). *Acute care nursing in the home: A holistic approach*. Philadelphia: J. B. Lippincott.
- May, K. A. (1991). Interviewing techniques: Concerns and challenges. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue*. (pp. 188-201). Newbury Park, CA: Sage
- Meleis, A. (1997). *Theoretical nursing: Developments and progress* (3<sup>rd</sup> ed). Philadelphia: Lippincott
- Melynk, B. M., Feinstein, N. F., Moldenhauer, Z. & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27 (6), 548-558.
- Mercer, R. T. (1995). *Becoming a mother: research on maternal identity from Rubin to the present*. New York: Springer
- Miles, M. S., D'Auria, J. P., Hart, E.M., Sedlack, D. A., & Wattral, M. A. (1993) Parental role alterations experienced by mothers of children with a life-threatening illness. In S. G. Funk, E. M. Tornquist, M. T. Champagne, & R. A. Weise (Eds.), *Key aspects of caring for the chronically ill: Hospital and home*.(pp. 281-289). New York: Springer.

- Miles, M. S., Holditch-Davis, D., Burchinal, P. & Nelson, D. (1999). Distress and growth outcomes in mothers of medically fragile infants. *Nursing Research*, 48 (3), 129-140.
- Miller, J. B. (1986) *Toward a new psychology of women*. (2nd ed.). Boston: Beacon.
- Neu, J. (1996). Necrotizing enterocolitis: The search for a unifying pathogenic theory leading to prevention. *Pediatric Clinics of North America*, 43 (2). 409-432.
- Noddings, N. (1984). *Caring, a feminine approach to ethics and moral education*. Berkeley: University of California.
- Nuttall, P. (1988). Maternal response to home apnea monitoring of infants. *Nursing Research*, 37, 354-357.
- O'Brien, M. E. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing*, 16 (1), 13-22.
- Okun, A. (1995). The history of respirators and total parenteral nutrition in the home and their use in children today. In J. D. Arres, H. W. Porterfield, & L. D. Porterfield (Eds.), *Bringing the hospital home: Ethical and social implications of high -tech home care* (pp. 35-52). Baltimore: John Hopkins Press.
- Parker, M. (2001). *Nursing Theories and Nursing Practice*. Philadelphia: F.A. Davis
- Patel, K., & Rushevsky, M. E. (1999). *Health care politics and policy in America*. Armonk, New York: M. E. Sharpe
- Patterson, J. M. (1988). Chronic illness in children and the impact on families. In C. S. Chilman, E. W. Nunnally, & F. M. Cox. (Eds.), *Chronic illness and disability*, (pp. 69-107). Newbury Park, CA: Sage.

- Patteson, D. M., & Barnard, K. E. (1990). Parenting of low birth weight infants: A review of issues and intervention. *Infant Mental Health Journal*, 11 (1), 37-56.
- Phillips, M. (1991). Chronic sorrow in mothers of chronically ill and disabled children. *Issues in Comprehensive Pediatric Nursing*, 14, 111-120.
- Phoenix, A., & Woollett, A. (1991). Introduction. In A. Phoenix, A. Woollett, & E. Lloyd. (Eds.), *Motherhood: Meanings, practices and ideologies* (pp. 1-12). London: Sage.
- Pridham, K., Lin, C., & Brown, R. (2001). Mothers' evaluation of their caregiving for premature and full-term infants through the first year: Contributing factors. *Research in Nursing and Health*, 24, 157-169.
- Pridham, K. F., Schroeder, M., & Brown, R. (1999). The adaptiveness of mothers' working models of caregiving through the first year: Infant and mother contributions. *Research in Nursing and Health*, 22, 471-485.
- Primeau, L. A. (1992). A woman's place: Unpaid work in the home. *The American Journal of Occupational Therapy*, 46 (46), 981-988.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Rich, A. (1986). *Of woman born: Motherhood as experience and institution*. (10th ed.). New York: W. W. Norton.
- Richards, M. P. M. (1983). Parent-child relationships: Some general considerations. In J. A. Davis, M.P. M. Richards, & N. R. C. Robertson (Eds.). *Parent-baby attachment in premature infants* (pp.61-84). .New York: St. Martin's Press.

- Ross, E. (1995). New thoughts on "the oldest vocation": Mothers and motherhood in recent feminist scholarship. *Signs*, 20, 397-413.
- Ruddick, S. (1995). *Maternal thinking: Towards a politics of peace*. Boston: Beacon Press.
- Rubin, R. (1984). *Maternal identity and the maternal experience*. New York: Springer.
- Sandelowski, M. (1989). The problem with rigor in qualitative research. *Advances in Nursing Science*, 8, 27-37.
- Shannon, K. A. (1990). The parents' perspective on pediatric home care. In P. A. McCoy & W. L. Votroubrek (Eds) *Pediatric home care: A comprehensive approach* (pp. 355- 378). Rocksville, MD: Aspen.
- Sims, S. L. , Boland, D. L., & O'Neill, C. A. (1992). Decision making in home health care. *Western Journal of Nursing Research*, 14 (2), 186-200.
- Skaff, M.M., & Pearlin, L. I. (1992) Caregiving: Role engulfment and loss of self. *The Gerontologist*, 32, 656-664.
- Spalding, K., & McKeever, P. (1998). Mothers' experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing* 13 (4), 234-243.
- Speigel, A. D. (1991). The economics of high technology home care: Doing right for the wrong reason. In M. J. Mehlman & S. J. Youngner (Eds.), *Delivering high technology home care* (pp. 23-66). New York: Springer.
- Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *IMAGE*, 12 (1), 20-23.

- Stewart, J. L. & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice: An International Journal*, 14 (4), 299-319.
- Strauss, A. (1988). Preface. *Social Science and Medicine*, 30, v-vi
- Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Strauss, A., & Corbin, J. M. (1988). *Unending work and care: managing chronic illness at home*. San Francisco: Jossey-Bass Publishers.
- Teague, B. R., Fleming, J. W., Castle, A., Kiernan, B. S., Lobo, M. L., Riggs, S., & Wolfe, J. G. (1993). "High-tech" home care for children with chronic health conditions: A pilot study. *Journal of Pediatric Nursing*, 8 (4), 226-232.
- Thomas, L. (1974). *The lives of a cell: Notes of a biology watcher*. New York: Penguin Books.
- Thorne, S. E., Radford, M. J., & McCormick, J. (1997). The multiple meanings of long-term gastrostomy in children with severe disability. *Journal of Pediatric Nursing*, 12 (2), 89-99.
- Thorne, S. E., & Robinson, C. A. (1989). Guarded alliance: Health care relationships in chronic illness. *IMAGE*, 21, 3, 153-157.
- Thurer, S. L. (1994). *The myths of motherhood*. New York: Penguin Books.
- Turner-Henson, A., Holaday, B., & Swan, J. H. (1992). When parenting becomes caregiving: Caring for the chronically ill child. *Community Health*, 15, 19-30.



- U.S. Department of Health and Human Services. (1988). *Report to Congress and the Secretary by the task force on technology-dependent children*. (HCFA Publication no. 88-02171). Washington, D.C.: U.S. Government Printing Office.
- U.S. Congress, Office of Technology Assessment. (1987). *Technology- dependent children: Hospital v. home care - A technical memorandum*. (OTA-TM-H-38). Washington D. C.: U.S. Government Printing Office.
- Vanderhoof, J. A. (1996). Short bowel syndrome in children and intestinal transplantation. *Pediatric Clinics of North America*, 43 (2), 533-550.
- Ward, D. (1990). Gender, time, and money in caregiving. *Scholarly Inquiry for Nursing Practice*, 4, 223-239.
- Ward, D., & Brown, M. A. (1994). Labor and cost in AIDS family caregiving. *Western Journal of Nursing Research*, 16(1) 10-25.
- Warda, M. (1992). The family and chronic sorrow: Role theory approach. *Journal of Pediatric Nursing*, 7, 205-210.
- Watson, L. (1991). Bonding and attachment: Myth or reality? *Professional Care of Mother and Child*, 91, 9-11.
- Weber, T. R., Tracy, T., & Connors, R. H. (1991). Short-bowel syndrome in children. *Archives of Surgery*, 126, 841-846.
- Weitzman, E. A. (2000). Software and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research*. (2<sup>nd</sup> ed) (pp. 803 -820). Thousand Oaks, CA: Sage.

- Whitbeck, C. (1984). The maternal instinct. In J. Trebilcot (Ed.), *Mothering: essays in feminist theory* (pp.185-192). Totowa, New Jersey: Rowman & Allanheld.
- Wills, J. M. (1983). Concerns and needs of mothers providing home care for children with tracheostomies. *Maternal-Child Nursing Journal*, 12, 89-107.
- Wilson, S., & Morse, J. M. (1998). Absolute involvement: The experience of mothers of ventilator-dependent children. *Health and Social Care in the Community*, 6, (4), 224-233.
- Woollett, A., & Phoenix, A. (1991) Psychological views of mothering. In A. Phoenix, A. Woollett, & E. Lloyd. (Eds.), *Motherhood: Meanings, practices and ideologies*. (pp. 1-12). London: Sage.
- Wong, D. L. (1991). Transition from hospital to home for children with complex medical care. *Journal of Pediatric Oncology*, 8, 3-9.

APPENDIX A  
SUMMARY AND CRITIQUE OF SELECTED RESEARCH

Appendix A  
 Summary and Critique of Selected Research on Technology Dependent Children at Home

Author(s)	Year	Study Participants	Methods/Tools	Findings	Limitations
Andrews & Nielson	1988	473 physicians, 12 nurses, 14 medical equipment distributors, 98 pharmacies, 74 mothers of monitored infants	Descriptive, content analysis/ Mailed questionnaire, follow-up phone calls	Study found that parents experienced technical equipment, family and financial problems	Disparate sample groups, limited geographic area
Hazlett	1989	15 mothers of ventilator dependent children	Descriptive/ Chart review, phone interviews, home care bills	Home care a tremendous financial burden to families, medically safe, stressful to mothers, better for child	Sample limited to mothers from one Midwestern hospital, no description of interview tool
McKeever	1992	25 mothers caring for technology dependent children at home	Critical theory/interviews, observation	Descriptions mothering these children using Ruddick's framework of maternal work	Sample restricted to one geographic area,

Summary and Critique of Selected Research on Technology Dependent Children at Home  
(cont.)

Author	Year	Participants	Methods/Tools	Findings	Limitations
Leonard, Brust & Nelson	1993	57 families of medically fragile children	Descriptive/Brief Symptom Inventory, Functional Level Form	High percentage of parents reported psychological symptoms indicating need for psychiatric intervention	Convenience, homogeneous sample, no discernment between hospital or home care causing more distress
Miles, Holditch, Buchinal & Nelson	1999	67 mothers of medically fragile infants	Descriptive/ Self-report questionnaires, semi-structured interviews, behavioral observation, and research team ratings of mothers	Mothers of medically fragile infants scored at risk for depressive symptoms but some mothers also experienced personal growth despite child's illness	Only one measure of stress and one measure of growth used, relied on observations for measure of personal growth, not self report, small sample size

**APPENDIX B**  
**RECRUITMENT FLYER**



## Mothers Caring for Children Dependent On Home Parenteral Nutrition (HPN)

Lorie Judson, an Assistant Professor at California State University, Los Angeles and a doctoral student at the University of San Diego, is conducting a study to describe the experience of mothering a child dependent on parenteral nutrition (HPN) so that this care may be recognized and understood in the health care community and beyond. If you would be interested in being interviewed for this important study, please complete information below. Interviews will last approximately one hour either in your home or a mutually agreeable location. No names will be attached to completed interviews. If you

have other questions, I may be contacted at:

(626) 794 - 3625 (H)

(323) 343 - 4719 (W)

Ljudson397@aol.com

Name \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Child's age \_\_\_\_\_

APPENDIX D  
CONSENT FORM



### Consent to Participate in a Study

Lorie Judson is a registered nurse, an assistant professor of nursing at California State University, Los Angeles, and a doctoral candidate at the Philip Y. Hahn School of Nursing at the University of San Diego. She is conducting a study to describe mothering a child at home dependent on parenteral nutrition.

If I agree to be a part of this project, I will be interviewed for approximately 60–90 minutes. If I agree, my responses will be recorded and documented in writing. The audio tapes will be kept locked in a filing cabinet and destroyed at the completion of the study.

My participation is voluntary and I have the right to refuse to answer specific questions or to refuse to participate at any time without jeopardy. My answers will not be identified with my name, as Lorie Judson will keep names separate from interviews in order to protect my privacy.

I understand if Lorie Judson observes signs of neglect or abuse at any time, she is obligated to report this to appropriate authorities.

I understand that I will derive no direct benefit from being in the study, but Lorie Judson hopes to learn more about mothers who are caring for children dependent on parenteral nutrition. I have talked with Lorie Judson about this project and have had my questions answered. I may reach her at (323) 343-4719 or (626) 794-3625 or by email at [ljudson397@aol.com](mailto:ljudson397@aol.com) or [ljudson@calstatela.edu](mailto:ljudson@calstatela.edu) if I have questions at a later time.

I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in this study.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of principal investigator

\_\_\_\_\_  
Date

APPENDIX E  
INTERVIEW GUIDE

### Interview Guide

1. Tell me how (child's name) became dependent on parenteral nutrition.
2. Tell me what it was like when you brought (child's name) home from the hospital.
3. Could you describe a typical day of caring for (child's name)?
4. How has caring for (child's name) changed your life?
5. What do you worry about?
6. What is the hardest part of caring for (child's name) for you?
7. Who gives you support and helps you?
8. Can you tell me about the most satisfying part of caring for (child's name)?
9. How would you describe the experience of feeding (child's name)?  
(Probe for - cues of hunger? How are mealtimes handled between child and rest of family? Does child eat by mouth?)
10. What would you tell another mother who was about to begin this caregiving experience?