

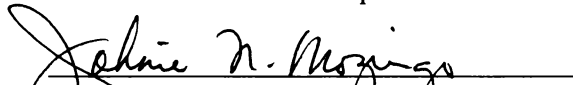
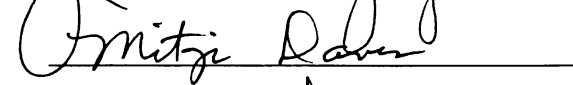
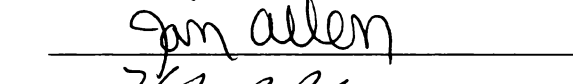
To the Graduate Council:

I am submitting herewith a dissertation written by Sharon Isenhour Sarvey entitled "Living with a Machine: The Experience of the Child who is Ventilator-Dependent." I have examined the final paper copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.



Sandra P. Thomas, Major Professor

We have read this dissertation
and recommend its acceptance.


Accepted for the Council:


Vice Provost and Dean of
Graduate Studies

LIVING WITH A MACHINE:
THE EXPERIENCE OF THE CHILD WHO IS
VENTILATOR-DEPENDENT

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee at Knoxville

Sharon Leigh Isenhour Sarvey

December 2001

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DEDICATION

To Jeff

ACKNOWLEDGEMENTS

This project really began many years ago, at the bedside of a tiny guy, nicknamed Kermit, in an intensive care nursery in eastern North Carolina. However, I would have never come to this point without the support, guidance and encouragement of so many special people.

It has been my great fortune to be guided by my dissertation committee chaired by Dr. Sandra Thomas and including Drs. Howard Pollio, Jan Allen, Mitzi Davis and Johnie Mozingo. Their commitment to interdisciplinary scholarship should be the standard. Without their vast knowledge, research experience, insight and wisdom this dissertation would have been a fleeting dream. I am additionally very grateful to all the faculty members who have taught me at the University of Tennessee College of Nursing. They have contributed immeasurably to my professional development. Finally, I wish to express my appreciation to the Gamma Chi Chapter of Sigma Theta Tau International Honor Society in Nursing for providing funding for this study.

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the tears. To Mom and Dad, thanks for being my first and best teachers. To Jeff: I'm back!!!.

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And finally and most importantly: To the children (and their parents) who were research participants with me: Thank you so much for allowing me the privilege to know and share you and your stories.

ABSTRACT

Children who are ventilator dependent have been living at home for some time now. Current research has considered home care to be the most appropriate environment for care of technology-dependent children with special health care needs. Research also has revealed much about the families who care for the children, the therapeutic management of their care and the efficacy of home care. No studies, however, have explored the experience of the child who has special needs, specifically those children who are ventilator dependent. There is an absence of first-hand knowledge about the experience of the children.

The purpose of this study was to describe the experience of the child who is ventilator-dependent. Interviews completed with nine children, using the phenomenological approach described by Pollio, Henley and Thompson (1997) and Thomas and Pollio (2002), yielded rich data from verbatim transcripts of the interview recordings and were interpreted by the researcher and the phenomenological research group in its weekly meetings.

The analysis of the transcripts revealed a thematic structure of the experience of being the child who is ventilator dependent as described by the participants. The meaning of the experience was contextualized by a ground of The Other: The Grown-up and the Machine and Never Being Alone. From this ground were revealed themes of I'm Still a Person!, Can/Can't and Normal/Different. The relationship of the study findings to

developmental theory and resilience theory was examined. The children who participated in this study did grow and develop as children are expected to do. Further, they were exemplars of resilience. Implications for nursing practice, education and future research were included.

TABLE OF CONTENTS

CHAPTER	PAGE
I. INTRODUCTION	1
Prologue	1
Historical Perspectives	2
The Current Population	4
Achieving Adulthood	5
Current Knowledge	6
Statement of the Problem	8
Methodological Approach	9
Qualitative Research	9
Nursing and Phenomenological Inquiry	11
Children and Phenomenological Inquiry	12
Purpose of the Study	15
Definition of Terms	16
Delimitations, Limitations and Significance	17
Delimitations	17
Limitations	17
Significance	17
Summary	19
II. LITERATURE REVIEW	20
Technology Dependent Children	20
Historical Perspectives	20
Children who at Home	21
Care Delivery in Evolution	21
Population Statistics	22
Social Costs	23
Reaching Adulthood	24
The Population of Interest	25
Effects of Long Term Hospitalization	27
Comorbidities	28
Physical and Developmental Implications for the Child	29
Developmental Implications	29

	Family Issues	30
	Challenges of Going Home	35
	Caring at Home	38
	Economic Considerations	39
	Ethical Considerations	42
	Children who are Ventilator Dependent	43
	Summary	47
III.	METHODOLOGY	49
	Existential Phenomenologic Approach	49
	Sampling Plan and Participant Recruitment	54
	Participant Inclusionj Requirements	55
	Human Subjects Protection	55
	Procedures for Data Collection	58
	Bracketing	58
	Data Collection from Participants	59
	Demographic Data	59
	Phenomenological Interviewing	59
	Data Analysis	60
	Interpretation of Findings	60
	Rigor	61
	Summary	62
IV.	RESULTS	63
	Demographic Characteristics	64
	The Participants	64
	Thematic Structure	71
	Diagram of Experience	72
	Contextual Grounds for the Experience	74
	The Other	74
	Themes	82
	I'm a Person!!	82
	Can/Can't	84
	Normal/Different	87
	Summary	89
V.	DISCUSSION	91
	Thematic Structure	91
	Relationship of Developmental Theory to the Study Findings	94
	Themes	97
	I'm a Person!!	97

Can/Can't	98
Normal/Different	100
Hearing the Voices of the Children	102
Relationship of Resilience Theory to the Study Findings	103
Implications for Nursing	105
Implications for Nursing Practice	105
Implications for Nursing Education	107
Implications for Nursing Research	109
Concluding Remarks	114
LIST OF REFERENCES	116
APPENDICES	129
Appendix A: Institutional Review Board Approval	130
Appendix B: Parental Information and Consent	131
Appendix C: Child Assent	132
Appendix D: Confidentiality Agreement for Research Group	133
VITA	134

LIST OF FIGURES

FIGURE	PAGE
3.1 Steps for Doing a Phenomenological Research Project	53
4.1 Thematic Structure: The Experience of the Child who is Ventilator-Dependent	74

*A champion is a winner,
A hero...
Someone who never gives up
Even when the going gets rough.
A champion is a member of
A winning team...
Someone who overcomes challenges
Even when it requires creative solutions
A champion is an optimist,
A hopeful spirit...
Someone who plays the game,
Even when the game is called life...
Especially when the game is called life.
There can be a champion in each of us,
If we live as a winner,
If we live as a member of the team,
If we live with a hopeful spirit,
For life
September 1999*

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CHAPTER 1

INTRODUCTION

Prologue

Years ago, late in the afternoon of a long shift a young nurse stood at the bedside of an infant who weighed a bit more than 500 grams when he was born. Now as he struggled to survive, she pondered the child's potential for a normal life that included the usual expectations for a children: bus rides to school, reading funny books, bicycle riding down hills, running with beloved pets, chasing waves at the beach and eating ice cream on a hot summer afternoon. She watched the child breathe assisted by a ventilator and also thought of recently posted signage outside the intensive care nursery door that declared the initiation of the "Baby Doe Hotline" by presidential (Reagan) mandate. All live-born children had to be resuscitated to the greatest extent possible. Not making such efforts would result in legal prosecution. In this neonatal intensive care unit, as in such nurseries across America, intensive efforts ensued to protect and maintain the lives of *all* live-born children regardless of their medical, social, cognitive or physical potential (Lyons, 1985). The nurse at the bedside considered what this tiny child would think about all that had been accomplished on his behalf. Who would he be? How would he grow and develop? What was his potential? What would he need to stay alive?

This study emerges from those moments of contemplation and the persistent absence of knowledge about the experience of that child and others like him who live

because of contemporary medical technology. Thus, the purpose of this study is to describe the experiences of those children who grow and develop while dependent on life-sustaining devices. The question specific to this study is, “What is the experience of the child who is ventilator-dependent?”

Historical Perspectives

Early in the decade of the 1980s a pair of courageous parents sustained by their personal beliefs finally received federal financial support and took their ventilator-dependent daughter, Katie Beckett, home to be cared for. Soon after, accounts of what other technology-dependent children required for care at home began to emerge in the literature (Staebler, 1986). At the same time, reports became public of the numerous benefits of home care for children who were medically fragile and technology dependent. Concurrently, reports also emerged emphasizing the extraordinary costs of continuing institution-based care for the same children (Cabin, 1985). Thus, the foundation was established for the rapid development of the then emerging trend to home care. O'Keiff (1986) spoke to this change in care delivery as she wrote, "Severely disabled children are not only 'technology-dependent' but also 'people dependent.'... The most realistic approach is to prepare for the care of children at home” (p. 55).

For many in a society oriented to perfection, children with chronic health care needs, especially those who are technology-dependent, are reminders of the glaring

reality that all cannot be perfect. During the 1982 workshop *Children with Handicaps and their Families*, sponsored by Surgeon General C. Everett Koop, national attention was drawn to the needs of this growing aggregate of children and their families. Children with severe chronic illness, particularly those requiring life-support devices, previously had no long-term residential options save institutionalization. By 1982 they increasingly were being cared for by their parents at home, making the need for appropriate resources paramount (Koop, 1997).

The Office of Technology Assessment (OTA) in 1987 published findings regarding "problems arising out of success" (p. iii). Many children experiencing chronic illness, the effects of birth trauma, or the sequela of acute illness and trauma, who previously may not have had any potential for survival were in fact surviving with the assistive technology available in high-level pediatric and neonatal intensive care units. These children were described as technology-dependent, meaning that they needed "both a medical device to compensate for the loss of a body function and substantial and ongoing nursing care to avert death or further disability" (OTA, 1987, p. 3).

Often the essential intensive care need was limited. Gottfried (1985) reported, for example, that of the 200,000 to 250,000 newborns in the United States who would for some reason require neonatal intensive care, required hospital stays averaged only 14-45 days contingent on gestational age and condition acuity. Many children, however, spent unnecessary weeks, months and years in the hospital. During these extended stays, the

children were as well as they possibly could be when assisted by technology and complex nursing care. Only with such ongoing support would they survive over time.

The OTA, in Technology-Dependent Children: Hospital v. Home Care, (1987) described technology-dependent children as "a small subset of the disabled child population who rely on life-sustaining medical technology and typically require complex, hospital-level care" (p. 3). At that time, the OTA estimated that there were some 2,000 children living in the United States needing ventilator support; 9,000 children requiring parenteral nutrition and/or long-term intravenous medication infusion; 6,000 children requiring device-based respiratory or nutritional support; 45,000 children requiring apnea monitoring; 6,000 children requiring renal dialysis and perhaps as many as 30,000 children requiring prolonged "device-associated" nursing care to compensate for impaired vital body functions.

The Current Population

In 1995, Center for Disease Control (CDC) reported that 6.5% of all the children in the United States experienced some degree of disability. Specifically, 3.8 million children in the United States were identified as disabled or impaired in some way with 25% experiencing severe impairments. While this percentage includes technology-dependent children, the number of technology-dependent children has not been specifically identified since the OTA document in 1987 (Newacheck et al., 1998). Chronic illness and disabling conditions in children have a tremendous social cost in both

fiscal and quality-of-life terms. Likewise, there is a strong association of economic and social disadvantage with disability and a substantial disparity in the impact of disability on children's health and social functioning (Newacheck, 1992; Newacheck et al., 1998).

Achieving Adulthood

Approximately 90% of children with disabilities will reach their 20th birthdays. This high likelihood of survival through the years of public schooling contributes to the significant 23.5 % increase in the special education population over the past two decades. Regardless of their disabilities children are legally eligible to receive resources available in the least restrictive environment, as legislated by the Individuals with Disabilities Education Act of 1992 funds (Betz, 1998). Further, resources for successful transition to adult living and employment are also legislatively mandated.

The Perkins Vocational Act of 1984 (and subsequent amendments) mandates that vocational education and employment services will be made available in all states for all youth with disabilities. Pertinent vocational education and employment services information is supplied to individuals and their families at least one year prior to entry into high school. Additional information must be provided just prior to the child becoming eligible for the services or available funds (Betz, 1998).

Transition into independent living was recognized as an ongoing and increasing challenge. There are currently nine national transition demonstration projects federally funded to develop new models for independent living (Betz, 1998). Moreover, some 26 federal programs focus on employment for (specifically) disabled individuals. These

programs both support and are supported by the American Disabilities Act of 1990 that guarantees the civil and legal rights of all disabled persons “thereby ensuring new opportunities for children and youth with disabilities” (Betz, 1998, p. 23).

Funding legislation of the past decade demonstrates an ongoing commitment to these special children at the national level. Medicaid waivers for children needing assistive technology in the home have provided fiscal resources to the child and family through the Omnibus Reconciliation Act of 1981. Children are additionally supported by Supplemental Social Security funds (Betz, 1998).

Current Knowledge

A search of literature published during the past two decades reveals that research is limited concerning technology-dependent children, also known as special needs children, and their families. Research has focused on therapeutic modalities, impact of care-giving for the family, the economics of care delivery, specific family concerns such as stress, the impact of the child in the community including the schools, and moral obligations to provide care for the children.

Researchers have demonstrated a number of benefits to home care for technology dependent children. Home care is more cost effective for these children than long-term institutional care (Burr, Guyer, Todres, Abrahams & Chiodo, 1983). Moreover, caring for technology dependent children at home clearly provides developmental benefits (Graham & Bryant, 1993). Children have both greater developmental potential and achievement

when cared for at home by encouraging parents and caregivers (Ahmann & Lipsi, 1991; Betz, 1998; Stutts, 1994). Home care is physically beneficial to these special children because they acquire fewer infections and experience improved physiologic outcomes when compared to children who are cared for in institutional settings (Fulcher, 1988; McCarthy, 1986). Moreover, parents truly prefer caring for these children and many parents have reported difficulty in trusting others to provide safe care. Parents report they often anticipate and fear disaster while they are away from the home (Coffman, 1998). Research also indicates that parents consider their family "better off" in spite of the rigorous nature of care for the special needs child who is technology dependent (Aday, Aitken & Wegener, 1988; Fields, Coble, Pollack and Kaufman, 1991).

Other literature encourages understanding the specific conditions children experience (Kohrman, 1994) and/or describes the children's concepts of illness (Yoos, 1994). Prevalent conditions and the persistent numbers of children affected by technology-dependence have been reported (Newacheck et al., 1998). The impact on schools and communities has been considered (Jones et al., 1996). The moral and ethical obligations and quality of life issues for families and communities of children with special needs have further been described (Arras, Dubler, & Neveloff, 1994; Lantos & Kohrman, 1992; Smith, 1994). A more comprehensive evaluation of this body of literature appears in Chapter Two.

Statement of the Problem

The significance of national legislative actions together with the body of research regarding children with special health care needs who are technology dependent cannot be understated. A wealth of knowledge has been disseminated in health care, social science, economics and popular literature of recent years clearly demonstrating the ongoing commitment to care for these children in this country. Yet, no first-person report of the experiences of the child who is dependent on life-supporting assistive technology has been located in the literature. Therefore the purpose of this study is to describe the lived experience of children who are technology dependent, and specifically ventilator-dependent.

For several reasons nursing provides the best perspective from which to engage in the study of the child experiencing technology dependence. While physicians usually prescribe therapeutic modalities, nurses are central to the care delivery model for children and families in the community. Nurses care for and educate the children and their families. Nurses assess, design, develop plans and arrange for specialized community-based home care as children and their families depart from acute and /or long-term institutional care. Further, nurses assist children as they grow to adulthood and evolve from dependency to self-sufficiency in community-based environments. Finally, nurses follow-up and evaluate specialized services with and for the young adult in the community, monitoring and facilitating efficacy in self-care.

Methodological Approach

Qualitative Research

While many use the term ‘qualitative research’ superficially to simply reflect a method of research that is non-experimental, Denzin and Lincoln write that “*Qualitative research* means different things... is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter” (1998, p.3). Qualitative researchers investigate things in the natural settings of the entities studied and in the context of the individuals or groups involved.

A qualitative approach encourages the interaction between researcher and research participant, is informal, has evolving decisions taking place regarding the questions asked, and has variable means of data interpretation. Qualitative research encourages inductive process. Categories of knowing and thematic patterns emerge to provide description of the phenomena of interest. Qualitative research methods are verified by returning to selected participants for their feedback concerning the findings revealed by the research.

Phenomenology

Phenomenology as a research methodology offers a holistic approach designed to thoroughly describe phenomena of interest through the lived experience of the individuals experiencing the phenomena. The phenomenological approach requires setting previous theories, experiences and biases of the researcher aside and entering the

process entirely open to the experience of those who have intimate experience with the phenomenon of interest. Thus, the process allows the researcher to “attain a first-person description of some specified domain of experience, with the course of the dialogue largely set by the respondent” (Pollio, Henley & Thompson, 1997, p. 29).

Phenomenology in nursing science is at once both a philosophy and a research method. Interpretation of data obtained from a phenomenological interview yields a rich description of a lived-experience rather than an explanation of cause and effect relationship. While phenomenological interpretation is based on the assumption of unique human experience, it does not “presuppose what meanings any specific experience will have for any specific person in some situation” (Pollio, Henley & Thompson, 1997, p. 46). Further, the interpretation of additional interview transcripts reveals “prominent meanings, relationships and patterns...” (p. 51) ultimately revealing “a specific thematic structure, describing specific experiential patterns and interrelationships among themes...” (p.52).

Phenomenology has its roots in European philosophy in the early twentieth century. Husserl’s thinking led away from traditional conceptual thinking of the time suggesting that the living present was the “absolutely original flux in and through which all temporal differences initially arise” (Macann, 1993). Heidegger extended Husserl’s work as he described that which phenomenology dealt with in “The Basic Problems of Phenomenology” (Heidegger, 1927, online). He expected to provide a “fundamental illumination of the basic problems of phenomenology by bringing out their inner

systematic relations” (Hofstadter, 1988, xvii). Phenomenology, according to Heidegger, sought to describe any phenomenon, “without theoretical preconceptions and wills only to unveil beings and being in their evident truth...” (Hofstadter, 1988, xvii).

Merleau-Ponty, whose phenomenology is thought to provide an excellent fit with nursing, further encouraged the description of the human experience in a holistic manner and chose perception as the most central to accomplishing description of human experiences (Thomas & Pollio, 2002). Thus, phenomenology requires not just a way of thinking, but a way of knowing. Moreover, phenomenology demanded an epistemology devoid of preconceived notions emerging from an all-inclusive worldview. Joining phenomenology to a philosophy of existence yields what is known today as existential phenomenology. Both philosophies emerge from a concerted effort to describe human existence through “rigorous description of human life as it is lived and as it is reflected upon in all its first person concreteness, urgency and ambiguity” (Pollio, Henley & Thompson, p. 5, 1997).

Nursing and Phenomenological Inquiry

Nursing requires a comprehensive research methodology in order to capture the meaning of various aspects of our patients’ lives that are not readily measurable (Thomas & Pollio, 2002). Utilizing phenomenological interview procedures is one such method for gaining insight and understanding into real and lived human experience. Such a method seeks to describe rich data of an experience from one who exists in and with the experience. The expected outcome of the research is an illuminating description of the

phenomenon of interest, in this case the experience of the child who is ventilator-dependent. “Phenomenological inquiry brings to language perceptions of human experience... Because professional nursing practice is enmeshed in people’s life experiences, phenomenology as a research method is well suited to the investigation of phenomena important to nursing” (Streubert & Carpenter, 1999, p. 43).

Children and Phenomenological Inquiry

Existential phenomenology is an appropriate nursing research methodology for use with children. Phenomenological interviewing gives study participants an opportunity to tell a very personal story about a particular experience of which they have unique knowledge. Children like to tell stories. Engle (1995) suggested that, “Children tell stories to organize their experience and their knowledge and to communicate that knowledge to others... stories not only reconstruct experience and communicate experience, they are experience... through the stories we tell about ourselves, we construct ourselves” (pp. 54-55). Children voluntarily participated in this study. They obviously enjoyed telling their stories.

Phenomenology was used previously in nursing research with children. The findings of some studies are relevant with regard to the population of interest, i.e. children who are ventilator-dependent. Murray (1998) described the lived experience of one fourteen-year-old sibling’s experience with childhood cancer. Complex themes of emotional intensity, increased empathy for others, personal growth, need for support and desire to help others emerged from this study. Coffman (1994) explored the lived

experience of Hurricane Andrew with seventeen children ages five through twelve who lived in the storm damaged area in Florida. These children articulated various aspects of life after the Hurricane based on their experiences of remembering the storm, dealing with after effects of the devastation and re-establishing life.

Findings of some studies reveal that children also describe various reactions to the experience of stressful events. Jacobson (1994) explored the meaning of stressful life experiences with 14 children, 9 to 11 years of age. The children identified 17 categories of situations concentrated within three principal dimensions: feelings of loss, feelings of threat to self, and feelings of being hassled. Participants indicated that experiences related to loss, although infrequent, were of great consequence in their lives. Hockenberry-Eaton and Minick (1994) sought to understand the experience of children receiving cancer therapy. Twenty-one children of varying ages (7-13 years) were interviewed regarding thoughts and feelings about their cancer and its treatment. Common themes of knowing, caring, feeling special and getting used to it revealed that children described patterns of strength and resilience in the stressful situations. Moreover, these results suggested that children should be aided, regardless of their cognitive development, to develop strength in situations of adversity. In a study published in 1994, Haase and Rostad explored the experience of children who completed cancer treatment. These researchers interviewed seven children between five and eighteen years of age who were in documented remission after completing cancer therapy within the last year. The six themes that emerged from the study (gradual realization of normal, recurrence of fears, completion,

seeking a new normal, modifying relationships, resolution and moving on) were developed into a dichotomous structure of celebration and hope and uncertainty and fear.

There is clear evidence of the viability of phenomenology for understanding the experiences of children even when these experiences have involved egregious violence. For example, Erickson and Henderson (1992) considered the experience of children witnessing family violence. Bennett (1991) focused a study of family violence on adolescent girls who had experienced family violence. These studies provided rich descriptions of specific experiences of children.

The present study of children who are ventilator dependent, both philosophically and methodologically, is entirely consistent with and even mandated by The Standards of Nursing Practice for the Care of Children and Adolescents with Special Health and Developmental Needs. Standard I criteria demand “Data collection is determined by the concerns and priorities of children, adolescents, their families and/or communities” (p. 11) Standard III outcome criteria require that “Outcomes... reflect the strengths, priorities, needs and language of children, adolescents...” (p. 13). Standard V criteria declare that “ethical expectations require the nurse to act as an advocate” (for the child). Thus, this study using the voices of the children who are ventilator dependent to describe their unique experience was consistent with the mandate called for in the aforementioned standards of care. Moreover, this study contributes to the development of nursing science and supports ongoing nursing practice.

The purpose of this study was to describe the experience of children who are ventilator-dependent using a phenomenological method of inquiry that results in a thematic description of the experience as reported by the children themselves. A developmentally appropriate question, which remained constant throughout the study, was posed to children who required a ventilator to survive. The broad question was: ***What is it like to be technology dependent?*** More specifically, the question that guided this study was: ***What is the experience of the child who is ventilator-dependent, as described by the child?***

Children, who are ventilator dependent, specifically between the ages of seven and twelve years of age, were the population of interest for this study. Breathing is both metaphorically and literally suggested to be the essence of life. While one can be sustained for indefinite periods without taking nourishment or fluid, one cannot be sustained without taking in essential air. By the age of seven, school age children are aware of themselves sufficiently to understand how important it is for them to breathe. Thus the school-age group was utilized so that they would be old enough to understand the process of breathing as well as be able to participate in an interview. This age group could give assent to participate and yet be free of the all too well known burdens of adolescence. It was this information and understanding that guided and informed the researcher in selecting this sub-group of technology dependent children.

Definition of Terms

Children with special health care needs are identified in various ways. The labels used are frequently inconsistent and may be confusing. For purposes of this study, specific labels were applied to participants, and medical devices have been defined from the author's perspective as derived from the author's experiences.

Child: an individual who is 7 to 12 years of age, inclusive

Technology-dependent child: a subset of the disabled child population who rely on life-supporting medical technology and typically require complex, hospital-level care... those who require " both a medical device to compensate for the loss of a body function and substantial and ongoing nursing care to avert death or further disability" " (OTA, 1987, p. 3)

Ventilator: device used on a continuous or intermittent basis to replace some or all of the essential physiologic functions of respiration and the biochemical processes of ventilation; to include: mechanical ventilators, portable mechanical ventilators, Bi-Pap machines (a device that provides intermittent force, positive airway pressure), cuirasses (negative pressure vest device to aid in the physical function of respiration), portalung (iron lung device), and CPAP (continuous positive airway pressure).

Ventilator-dependent: requiring the use of an aforementioned device on a continuous or intermittent (at least eight of every 24 hours) basis to replace the essential physiologic function of respiration

Delimitations, Limitations and Significance

Delimitations

This study was designed to describe the experiences of the child who is ventilator-dependent. To that end, the design was delimited to children who require such a device to survive. They described their experiences during unstructured, phenomenological interviews.

Limitations

A limitation of this study was that it focused on only the experiences of children who are technology dependent. The research design was qualitative interpretational phenomenological, and the limitations of that approach apply. The sample selected was limited in size. The children were all very different in their need for artificial respiration which will be further discussed in later chapters. The data may be open to other interpretations and other researchers may expand upon the findings. Moreover, the purposive nature of recruiting participants limits the applicability of the findings to all children who are technology dependent as does the geographic location and living arrangements of the participants.

Significance

Of greatest significance, this study contributes to the body of knowledge about the day-to-day experience of children who are ventilator-dependent. While much is known about these devices and therapeutic modalities to which technology-dependent children

are subjected as well as the experiences of the parents and other caretakers, there is virtually nothing known about the experience of the child. This research will fill that gap. In addition, this study has numerous implications for nursing practice. Research explicating the phenomenon of living with a machine from the perspective of the child who is dependent upon that machine will assist nurses to better appreciate the unique needs of this exceptionally vulnerable population in a wide variety of circumstances including the acute care setting, the home, the school and the greater community. It was expected that results of this descriptive research will inform further assessment and research concerning this vulnerable population.

Finally, this study enhances policy and program planning for these children as they grow up and become independent in their communities. Currently, the perspectives and values from which program planning and policy formation proceed included little knowledge of the experiences of the children for whom the programs and policies have been rendered. Indeed, others have been speaking for the children. Teaching what the individual needs to know, providing what the individual needs and desires, and educating the individual to empower their self-sufficiency are the hallmarks of holistic nursing. Policy and program planning for this small but very important group of young people will potentially be enhanced and more successful with this new information available.

Summary

“How visible and important are children in society? Are they valued? Are they viewed as an asset, a neutral element, a liability? In recent years, children’s issues have

found their way into political rhetoric, but rarely as serious, central, or dominant themes” (Palfrey, 1995, p. 20). Often considered the most vulnerable of all populations, children depend nearly entirely on the perspectives and values of those who are not children. Children, especially those with severe chronic illness necessitating assistive technologic devices, are especially vulnerable to perspectives and values others hold about their needs.

This study was motivated by a need to give voice to the experience of a child who lives with a ventilator. As demonstrated in the brief review of contemporary research literature, almost nothing is known regarding the first-hand experiences of the child. This study, which is concerned with describing the experience of the child who is ventilator-dependent, informs nursing practice, education and research by closing a gap in the literature and by enhancing professional practice with this exceptionally vulnerable population.

CHAPTER 2

LITERATURE REVIEW

The purpose of this study was to explore phenomenologically the experience of the child who is technology dependent, specifically, ventilator dependent. In this chapter, an overview of current knowledge regarding technology dependent children is given. This overview includes definitions, demographic information, social and economic concerns, transitioning to adulthood and issues of home care giving. Studies specifically considering ventilator dependent children were also been reviewed in this chapter.

Technology Dependent Children

During the 1982 workshop *Children with Handicaps and their Families*, sponsored by Surgeon General C. Everett Koop, for the first time national attention was drawn to the needs of this growing aggregate of children and their families. Children with severe chronic illness, particularly those requiring life-sustaining devices, previously had no lifelong living option save institutionalization. By 1982, however, they were increasingly being cared for by their parents at home (Koop, 1997).

Historical Perspectives

It was not until the 1980's that a trend for home care of chronically ill, technology-dependent children began to emerge. In 1981, President Ronald Reagan initiated the first Medicaid waiver to insure continuing financial support for home care

for Katie Beckett, a child who required constant mechanical ventilation after a bout with meningitis. This first 'Katie Beckett waiver' came after three years of unnecessary hospitalization because Katie would have lost financial support from Medicaid if she were cared for outside the hospital. Katie's parents could now care for her at home and receive federal fiscal support. The issue was brought into the public domain.

Children who are Technology-Dependent at Home

Prior to the 1980's, technology-dependent care had usually required that the child be cared for in the hospital. Specifically, this care was provided in the neonatal or pediatric intensive care units. Not infrequently, the care was provided in various adult or specialty (surgical, neurological, medical) intensive care units. Following Katie Beckett's arrival home, accounts of what the special needs child required for care at home began to permeate the literature. The November, 1986 issue of Caring, was entirely devoted to the ongoing experiences of parents and their special needs children especially those who required complex supportive technology (Staebler, 1986). With the move toward financial restraint, the enhanced technology available in the home, and a developing philosophy of family-centered care, the home care movement for technology-dependent children was underway.

Care-delivery in Evolution

Home care for children who are technology-dependent is a care-delivery model in evolution. Children are being cared for at home: a change in location, and from a

community perspective, a change in focus. Stein (1984) defined the significance of this change:

Care of children with significant chronic illness may best be defined as an attempt to normalize the care of the child...in a family and community context and setting, in order to minimize the disruptive impact of the child's condition and to foster the child's maximal growth and development (p. 3).

Research explicating the move of children with life sustaining assistive technology from institutional care to home care, however, still lacks input from the child as he or she experiences specialized technology-dependent care in the home.

Population Statistics

In 1987, the Office for Technology Assessment, in Technology-Dependent Children: Hospital v. Home Care, (1987) described technology-dependent as "a small subset of the disabled child population who rely on life-sustaining medical technology and typically require complex, hospital-level care" (p. 3). Data from the 1992-1994 National Health Interview Survey indicate that 31% of all children, 18 years of age or less, have one or more chronic health care issue, excluding chronic mental health and learning disabilities, and 6.5% of all children in the United States experience some degree of disability (Newacheck & Halfon, 1998). Some 9% of children have moderately severe conditions that affect the lifestyle of the child and 2% have conditions that lead to regular limitation of daily activities (Newacheck & Taylor, 1992). Childhood disability is

estimated to result in 66 million annual days of restricted activity, 24 million days lost from school, 26 million physician contacts and 5 million hospital days (Newacheck & Halfon, 1998).

Social Costs

Chronic illness and disabling conditions in children have tremendous social costs, both in fiscal and quality-of-life particulars. Newacheck and Halfon (1998) cite the prevalence and effect of chronic health conditions experienced by children. A higher prevalence of disability occurs in males, children of poverty, and those in single parent households.

The strong association of economic and social disadvantage with disability is a matter of concern as is the substantial variation in the impact of disability on children's health and social functioning. Data reveal that of the 4.4 million children identified as disabled, 2.7 million are limited in some major activity, 1.2 million are somewhat limited and .5 million are unable to conduct any major activity. Over 1.2 million of these children come from poor families, nearly 2.4 million are male and over 1.5 million are geographically located in the south. Moreover, children with disabilities are usually cared for by parents who experience unrelenting care giving demands and lost income because of requisite unemployment. Finally, expenditures for healthcare have been demonstrated to be substantially higher for children with disabilities (Newacheck & Halfon, 1998). Despite the clarity of these statistics, a true picture of the technology-dependent children

is currently unknown and counts of children who dependent on particular therapeutic devices are not available.

Reaching Adulthood

The approximately 90% of special needs children who live to reach their 20th birthdays spend much of their time, during those years growing-up, in public school. Children who are technology-dependent have contributed to a tremendous increase in the special education population in the past two decades as noted in Chapter One. There is a noteworthy concern for these children in the education literature and many questions have arisen regarding the management of technology dependent children in the classroom. Legislators remain confounded by the cost of relevant health care requirements for special education children. While some parents are suing school boards to obtain access for their technology dependent in regular classrooms, other parents are suing for their children to have the right to play soccer despite their assistive devices. Therapeutic day care and playgrounds are becoming a reality, and all children regardless of their disabilities must have free educational resources available in the least restrictive environment (Betz, 1998). Moreover, Medicaid waivers for children needing assistive technology in the home have provided fiscal resources to the child and family through the Omnibus Reconciliation Act of 1981; in addition, children are supported by Supplemental Social Security funds (Betz, 1998). The benefits and continuing challenges of all programs for children with special health care needs as well as their true costs are currently unknown.

The Population of Interest

There has been inconsistency in delimiting the population of technology-dependent children. The Task Force on Technology-Dependent Children (U. S. Department of Health and Human Services, 1988) first defined the population as:

A person from birth through 21 years of age (a person who has not reached his/her 22 birthday); who has a chronic disability; and requires the routine use of a medical device to compensate for the loss of a life supporting body function, (for example, dependence on mechanical ventilators or other device-based respiratory or nutritional support, including tracheostomy tube care, oxygen support, intravenous and enteral tube feeding); and requires daily on-going care and/or monitoring by trained personnel (p. xiii).

In a document prepared for foster parents of technology-dependent children in Kentucky entitled Caring for the Medically Fragile Infant with Life Threatening Conditions, (Worth, 1990) high risk and medically fragile infants and children were further described as:

at risk for abnormal growth and development and other serious problems including death. ... problems stem from complications associated with premature birth, a variety of medical disorders, various physical abnormalities, and problems in the child's home environment...who have a condition documented by a physician which can become unstable and

change abruptly resulting in a life threatening condition...(who) need medical and supportive treatment and continuous monitoring, but their care needs do not necessarily require the daily services of a doctor or a nurse to ensure their medical safety (p. 7).

For the current study, children who are technology-dependent were defined according to the Task Force on Technology Dependent Children (U. S. Department of Health and Human Services, 1988) with the caveat that: (a) the mechanical dependency may have pathologic, physiologic and/or accidental antecedents, (b) the child's condition can change abruptly and become life-threatening, and (c) the child needs constant monitoring and care but not necessarily by a physician or nurse.

There are limited research findings about these children, specifically those dependent on particular therapeutic modalities. Many of the children continue living as survivors of prematurity, accidental injury or rare physiologic disorders. Many of the children require multiple life sustaining assistive technology devices including ventilators, oxygen delivery systems, nebulizers, enteral feedings, parenteral feeding, complex medication administration, peritoneal dialysis and cardio-respiratory monitoring. They have experienced many hospitalizations and painful procedures (Judy Harrison, personal communication, March 7, 1997).

Effects of Long-term Hospitalization

As noted, children dependent upon technologic devices to survive may spend an extraordinary length of time in the hospital because of inadequate resources for their care

in the home. After investigating the effects of long-term hospitalization on children, Yoos (1998) noted that the hospital environment was over-stimulating, inconsistent, painful and artificial. Often hospital units were a great distance from the family home and family visitation was limited. Under these circumstances, children were lonely and experienced concerns that were not related to their disease conditions. Yoos found that often children remained hospitalized for months and became angry, withdrawn and hopeless. In addition to the tremendous stress on the family simply because of their technologically dependent child, there were additional stresses related to communication, travel, and care for other children and potential unemployment. Certainly the child in a strange, lonely, hospital environment, cared for by strange people and dependent on various "monster-like" machines (Kohrman, 1994) was at least as stressed as his or her parents and other family members.

Noyes (2000) recently reported a study of ventilator-dependent adolescent males in Great Britain and their experiences in the hospital setting. In this qualitative study of 18 young men, many of whom had communication impairments because of their technology dependence, Noyes investigated health needs, social needs, environmental needs, education needs and aspirations for the future. The findings revealed a compelling picture of the lack of respect, the violation of human rights and the discrimination perceived by these articulate young people. They reported being forced to remain in the hospital unnecessarily, not being able to maintain contact with their families, and being

discriminated against for seeking health care and not being allowed to make important decisions in their lives because they were required to live with a machine.

Comorbidities

Researchers have demonstrated a persistent comorbidity of mental health concerns in this population. Estimates of the prevalence of psychological problems secondary to chronic health conditions range between 10% and 30% and it is clear that such needs are not adequately addressed (Newacheck & Taylor, 1992). Vessey (1999) suggested that although the majority of children with chronic conditions were “amazingly resilient and adapted well to the challenges of their conditions, the identifiable problems in this cohort is about 20% or twice that of healthy children” (p.1). Vessey further described suggest such mediating factors as the child’s general health status, family functioning, the child’s gender, age and developmental level, parent and child perceptions and expectancies and familial flexibility and cohesiveness.

In a comprehensive review of psychosocial interventions for children with chronic health concerns, Bauman et al (1997) found fifteen studies that sufficiently reported some model utilized for psychosocial intervention. Positive results, including measures of improved self-management and knowledge were reported, although in general there was limited evidence of intervention efficacy in most of the studies. Recommendations included larger sample sizes, process evaluation, and more comprehensive evaluation of methodologies used and outcomes identified. On reflection, there are additional concerns. First, the models reviewed and explicated reflected on children who were in home care

but not dependent on technology. Additionally, all measures used to evaluate program effectiveness were quantitative measures of content acquisition, behavior management, family stress, or maternal satisfaction to name but a few of the variables being examined. Finally, there was no indication that any researchers actually spoke with the children in question about their mental health concerns.

Physical and Developmental Implications for the Child

Prior to the opportunity for home care, devastated families of children who had become technology-dependent often came to the painful conclusion that they had no options for long-term care except for that provided in a hospital setting. Moreover, there were few places for parents to obtain assistance or care that was developmentally appropriate. Children were placed in adult nursing homes and occasionally foundling homes when abandoned by parents or other caregivers. Generally, these children had physical and developmental disorders that had little potential for recovery or rehabilitation. Hence, the developmental benefit to the child that home care provided became another issue on which to focus for persons advocating for children experiencing prolonged hospitalization.

Developmental Implications

Children who are technology-dependent are considered to be "developmentally" fragile (Stutts, 1994). Children in situations of prolonged hospitalization are at risk for developmental delay, and developmentally supportive care must be provided by parents and other primary caregivers (Graham & Bryant, 1993; Schreiner, Donar & Ketterick,

1987). Developmentally appropriate care provides enhanced opportunities for children to achieve optimal physical growth, social development and gross motor skills. Children with adequate cognitive function should have opportunities to learn to manage developmental issues similar to healthy members of their age group (Yoos, 1988). Thus home care is beneficial to the child as related to both developmental concerns and physiological concerns: home care for children reportedly acquired fewer infections with less severe outcomes simply because of less exposure to infection (Fulcher, 1988; McCarthy, 1986). While the value of home care for enhancing the developmental outcomes of the child is clear from these empirical reports, there is no evidence of the value of home care as experienced by the child. Understanding the experience of the child who lives with a machine at home should contribute a needed dimension to this literature.

Family Issues

Often parents express positive thoughts concerning home care for their technology-dependent children. They consider both the children and the family to be "better off" when the child is cared for at home. The care of the chronically ill/technology-dependent child at home, however, requires unique adaptation to changes in the family (Fields, Coble, Pollack & Kaufman, 1991; Fleming et al., 1994). Teague et al. (1993) described the children and their families experiencing the phenomenon of home care for technology-dependent children. The interview study surveyed 73 caregivers of technology-dependent children. In addition to demographic data about the

children, this study also yielded demographic information about the primary care givers for the children. Findings revealed caregivers were predominantly mothers (81%), approximately 36.7 years old, married (72.6%), high school graduates (34%) or college educated (40%). Many of the caregivers (41.1%) had employment outside the home. Of the primary caregivers, 37% reported limiting their working outside the home to allow for the care requirements of their technology-dependent child at home. Caregivers reported that caring for the child was a rigorous physical challenge (62%). The children were demographically identified as being 49.3% female and 50.7% male. They were primarily impaired by neurological or respiratory dysfunction (52 % total). Further, according to caregivers, the children were developmentally below normal (63%). Despite these results, those interviewed did not report the impact of the child's condition and care as totally detrimental or negative to the family. Some 90% of the caregivers even suggested that the situation they were experiencing was of benefit to their family and made them a "better family." Additionally, 90% of the respondents reported that learning to manage their child's care made them feel better about themselves.

The Teague et al. study is clearly in contrast to Boland and Sims (1996) description of a grounded theory study used to better understand the care giving experience from the perspective of caregivers. Seventeen families from a metropolitan intermountain western area comprised the sample. Recipients of care ranged in age from 14 months to 87 years. People with documented mental illness, dementia, or Alzheimer's disease were excluded from the sample. Interviews were conducted in participants' homes

and data were analyzed through constant comparative analysis. The central idea emerging from the data was that care giving was a “solitary journey.” Burdens of the care giving demand, responsibilities perceived by the caregiver, isolation from others, and commitment to the recipient of care shaped the context of the so-called “solitary journey.”

The family of the technology dependent child was found to be socially marginalized in Cohen’s (1999) grounded theory study of the two-year transition of technology dependent children from the hospital to the home. Comprehensive data collection included participant observation, interviews with family caregivers, health professionals and community members, videotapes and reviews of relevant literature. Initial reports of the data note significant moral distress and change in social trajectory for the family limiting interactions of the family members outside the home.

It is not surprising that families caring for technology-dependent children at home consider themselves to be socially isolated, chronically fatigued and in need of adequate respite care in spite of on-going comprehensive home care plans (Andrews & Neilson, 1988; Petr et al., 1995; Stevens, 1991). Coffman and Folden (1992) noted that families of medically fragile children need significant networks of support:

Balancing the needs of a medically fragile child with the needs of other family members requires that parents of medically fragile children have good physical health and stamina, an emotionally strong marriage and family interaction, a support network of family and friends, and adequate

financial resources. The absence of one or more of the above resources makes it difficult for families to maintain a satisfying life style and provide adequate care for their medically fragile child. Respite services may provide the needed support for families to maintain their personal resources and prevent potential burnout that 24-hour care taking can produce (p. 18).

Yet, Salisbury (1990) found only 32% of families who had respite care available took advantage of their resource. Parents who reported difficulty in trusting others to provide safe care often anticipated and/or feared disaster occurring with their child while they were away from the home.

Youngblut, Brennan and Swegart (1994) assessed everyday problems in the home, family coping strategies and family resources with a limited convenience sample of ten families of medically fragile children who varied in age from one to ten years. The children required various devices and had variable medication regimens. To identify stressors, families were asked to identify recent decisions they had to make and their primary resources for assistance in decision-making. Families were asked to identify major problems faced in caring for the child. It was fascinating that this study's stated intent was to identify coping mechanisms yet failed to do so. Rather, the study described evidence of problem solving for issues such as whether therapeutic treatments should supersede the child's need for a nap. One certainly would wonder how the children might reflect on the (albeit limited) findings that families relied mainly on physicians, physical

and occupational therapists and the school system to support their decision- making processes.

In contrast, Thyen, Kuhlthau and Perrin (1999) investigated the impact on maternal health of long term caring for a child who is technology dependent. Citing the first year after hospital discharge as being particularly stressful, a cross-sectional study comparing families with and without technology dependent children was undertaken to investigate the mother's general and mental health and family functioning six months after a child's first hospitalization. Using various measures of maternal health and emotional well being, maternal health outcomes were determined. In addition, socioeconomic data and functional severity of the child were assessed along with family functioning and social support indicators. The study group (n=65) reported poorer health status generally and mentally. Role performance and social functioning, and vitality were less for the study sample. Additionally, the mothers expressed more bodily pain than did the comparison group (n=54). The mental health comparison was significant at $p < .01$. Interestingly, this difference occurred in spite of little difference in socioeconomic variables even taking into consideration the percentage (67.7%) of mothers who had worked out of the home previous to caring for the technology dependent child at home (n=44). Moreover, there were significant differences in family functioning with study group mothers reporting less cohesiveness and expressiveness. The researchers found no significant difference between groups in conflict in the family.

Families of ventilator-dependent children, who require some of the most complex care of all special needs children have also been studied. Aday, Aitken and Wegener (1988) reported the results of a study conducted over a three-region area and found that while the care of technology-dependent children is often described as a "burden," parents still prefer to provide care for their children at home especially because financial stress is part of the burden (Hazlett, 1989). Family-centered care has been identified in the literature as being an optimal model of providing care for children, generally, and for home care for technology-dependent children, specifically. Family-centered care in child health care "recognizes families as central in the child's life and their values as priorities central in the plan of care" (Ahmann, 1994). Family-centered care recognizes the uniqueness of all families and their members and may help to abate the misplaced contention by some that home care professional nurses come into the home to 'fix' what has been (incorrectly) identified as 'broken' (Ahmann, 1994, Patterson, Jernell, Leonard & Titus, 1994; Petr, Murdock & Chapin, 1995; Smith, 1991; Stevens, 1991; Stoller & Pugliese, 1989). Family-centered care that fosters linking of individuals with services and other resources were mandated by public policy and requires individualized plans for each recipient of care (Bond, Phillips & Rollins, 1994).

Challenges of Going Home

Although many parents articulate their desire to care for their technology dependent children at home, problems arise to hamper even the most determined. Simply going home proves a challenge. In a comprehensive intervention discussion published in

two parts in 1994 (April and June), Wells et al. (1994a, 1994b) remind us of the extensive body of knowledge regarding children growing up in the hospital and proposed a model Child Life program to foster all aspects of development for children who experienced long term hospitalization. While this particular model focused on care in the hospital, the children were candidates for discharge to home. The program included a thorough assessment of the family life with a commitment to the special needs of families. The plan included participation in the program within "new" parenting roles and recognized the impact of parenting a child with long-term medical needs. There was a focus on the optimal environment, effective, efficient and timely communication between caregivers as well as within the family. Included also, were plans to assist the family with functional needs such as care for and inclusion of siblings. In this particular program, great emphasis was placed on planning to prepare the child and the family for transitioning home. This approach reportedly enhanced discharge and is consistent within the model of family-centered care (Bond, Phillips & Rollins, 1994). This intervention has not been systematically evaluated and outcome data have yet to be collected.

Geography appears a particularly difficult challenge to overcome. Wheeler and Lewis (1993) considered the difficulties encountered as families in both urban and rural communities attempted to take their technology-dependent children home. The Specialized Home Care Program (SHCP), a managed care program designed to support and enhance the care of medically fragile/technology dependent children in widely diverse community settings, provided the mechanism to compare the challenges of going

home in both urban and rural settings. Wheeler and Lewis (1993) reflected on care to 200 children in natural or foster homes widely distributed throughout Michigan. Their anecdotal, descriptive findings indicated that there were many comparable difficulties including specifically, inadequate nursing care both in numbers and knowledge of particular needs. There was a reported inadequacy of respite options. Local health care providers were unable and often unwilling to care for the special children and poor coordination of medical services left children without primary providers or efficient emergency medical care. In spite of legislation to the contrary, both public and private schools had access issues that were often as simple as ramp access.

According to Wheeler and Lewis (1993), rural settings for technology-dependent children reportedly challenged the family caregiver to an even greater degree. Small communities, unstable water supplies, inadequate emergency medical services, frequent power outages and insufficient professional resources (in both number and training for the special needs child) provided but a few of the concerns. Wheeler and Lewis recommended careful assessment of local resources prior to discharging the child. Professional experience reveals, however, that in poor rural counties, there are few resources to support these families. There is a scarcity of emergency medical personnel equipped to assist in a crisis. Home care nurses are often unavailable and those who are available are often incompetent caregivers (J. K., mother, personal communication, August, 2001). This concern has been echoed in the home health agencies where services available to children with special needs are limited and generally understaffed (Marley

Auerbach, personal communication, April 1, 1997). As one mother from rural eastern Kentucky said to a foster mother of medically-fragile/technology-dependent children, as she relinquished her parental rights and left her baby in foster care, "Thank God you came to get her. I can't do it anymore, alone." The biologic mother had been charged with medical neglect of her tracheostomy-dependent, gastrostomy-fed daughter with bronchopulmonary dysplasia (Judy Harrison, personal communication, January 14, 1997). The inconsistency of resources remains troubling. As previously noted, there is a scarcity of resources, especially home care nurses in many areas. Yet, in Massachusetts, children have been returning home on ventilators with family members since the 1970s and resources are available for their care (Burr, Guyer, Todres, Abrahams & Chiodo, 1983; Clark, 1990).

Caring at Home

In her comprehensive review of home health literature, Barkauskas (1990) reported that the history of home health in the United States had no reference to children outside of health promotional maternal-infant programs. "Home health was initiated for the care of the poor sick, who had limited choices among options for health care and has endured as an integral part of the American health care system" (p. 103). Barkauskas indicated that research on home care for children (beyond infancy) focused on: "the safety of children discharged with complex treatments or for severely disabled, chronically ill children; the ability of families to care for such children at home; and the

use of home care as a parent substitute for mildly ill children needing to stay home from school” (p. 112). How far home care for technology-dependent children has yet to go!

It appears that benefits vary for families caring for the child who is dependent on life-sustaining assistive technology at home. Certainly, empirical data is limited, with few studies reporting usable data. Additionally there continue to be difficulties in various aspects of care such as lack of resources and delays in hospital discharge due to unavailability of caregivers. Moreover, the children have not been asked about their experiences.

Economic Considerations

As the high cost of technology-dependent care mandated consideration of home care for children with life sustaining assistive technology, the families of these children have historically had few agencies or programs to assist with fiscal demands. Federal programs to support home care finally became available by 1982.

Home care is far more cost effective than hospital care. In a benchmark study reported by Burr, Guyer, Todres, Abrahams and Chiodo (1983), six families with ventilator-dependent children in the home were identified and interviewed. Families were asked to collate and calculate their child's care costs for a month. Copies of bills gave the researchers verification of the dollar amounts recorded. Analysis revealed home care costs to be 50% to 95% less than the same hospital care. Pediatric intensive care unit charges evaluated by Lawrence (1984), were estimated to be in excess of \$10,000 per week for a ventilator-dependent child as compared to \$10,000 per month for the same

care in the home, a 75% decrease for home care. Review of these studies demonstrates clear financial advantages to home care. These findings, however, are possibly not applicable in all situations where a technology-dependent child is cared for in the home, because ventilator-dependent children require the most costly care (Fields, Coble, Pollack, & Kaufman, 1991).

As the numbers of children requiring technology-dependent care increased due to advancing medical technology (Andrews & Nielsen, 1988; Burr et al., 1983; Gillis et al., 1989; Mausner, 1995; Newacheck, 1989), the rate of growth in home care industry requiring sophisticated technology has been dramatic. "High-tech home care has emerged from near total obscurity to become the fastest growing sector of the entire health care economy, providing valuable benefits to hundreds of thousands of patients per year and earning billions of dollars for innovative and adventuresome companies" (Arras, 1994).

Despite such increases, cost reduction benefits from technological home care do not continue to be as large as initially assessed. Reviewing the financial effects of high-technology home care Arno et al (1994) noted that 1970 hospital costs compared to home care costs at a ratio of 279:1. By 1991, the fiscal savings had dropped to approximately 29:1. Arno et al. noted that home care had "increasingly become an alternative to hospitalized care rather than just a means to recover from it" (p. s15). With regard to infusion therapy, frequently utilized at home for children as well as adults, Arno et al. further indicated that "solutions, medications and delivery systems are expensive and growing more so" (p. s16-17). Additionally, the authors found that when infusion therapy

is required, frequently the family is unable to manage the direct care giving involved and must have outside professional assistance. Hence, costs for infusion therapy alone between 1987 and 1993 were reported to have grown \$2.3 billion, an increase of over 200% (Arno et al., 1994). In 1987 for example, expenditures for home care in the United States were approximately \$4 billion. By 1994, the dollar amount was expected to top out at \$22 billion (Arno et al., 1994).

Even though comprehensive home care costs for technology-dependent children have not been thoroughly assessed since the publication of Technology-Dependent Children: Hospital v. Home care in 1987, it remains clear that costs are staggering. A report from the Social Security Administration (December, 1996) reported that 1,017,000 children received Social Security income, a major financial resource, averaging approximately \$440. This reflects figure only a portion of the actual costs incurred in caring for children with technical dependence. Furthermore, while the costs have been considered and are indeed quite important in the evolution of home care for the child who requires life-sustaining assistive technology, the actual experiences of the child as related to the fiscal benefits of home care have not been considered.

Ethical and Moral Considerations

Questioning the ethics of home care for children who are dependent on life-sustaining assistive technology, Arras, Dubler and Neveloff (1994) consider whether moral support should be given in such a difficult situation or moral obligation overrules pragmatic decision-making about long-term assistive technology for those with little

opportunity of a quality life. A project of the Hastings Center (reported in a special supplement to the June 1994 Hastings Center Report) suggests that “high-tech home care” is a complex phenomenon where the “traditionally private sphere of the home” is intruded upon by medical therapeutics. Problems of meaning relating to body image and family member identity occur, and excessive burdens were placed on family members and friends who often are unprepared for the demands of their new roles. This type of home care was often disorganized and may or may not be better than hospital care. Yet, the industry supporting this care has reaped tremendous financial rewards. Costs soared while empirical evidence is lacking concerning the cost efficacy of particular therapeutics (Hastings Center Report, 1994). Moreover, it has been well accepted that women provide the predominance of care to these dependent children, managing complex situations likely to change, often from moment to moment. Questions still abound regarding the duration of therapeutic devices: “Is the patient tethered to the machine for a life of indefinite duration or only for a short time? Is the purpose of the treatment merely palliative or is it meant primarily to restore health or extend life?” (Arras, Dubler & Neveloff, 1994, p. s19). What is the quality of life for the patient? What is the perspective of the child to whom the care is delivered? What is their existence? While it is indeed philosophically important for ethicists to consider dilemmas of this nature, it is also appropriate to consider the experience of the children as they reflect upon living with a machine.

Children who are Ventilator Dependent

As previously noted, ventilator dependent children are both the most costly and most difficult to care for. Comprehensive review of allied health literature reveals studies of medical therapeutics, weaning parameters and guidelines for care over the long term. Yet as has been noted, there is a paucity of literature examining the experience of children who are ventilator dependent.

The earliest mention of artificial breathing for children was in the Bible where it was reported that Elijah used mouth-to-mouth respiration to revive a child. The first theoretical proposal for mechanical ventilation appeared about 1543 with the first mechanical ventilator not developed until 1743 by Stephen Hales. The hand-operated device used bellows to artificially inflate the lungs. The most primitive version of the iron lung, a negative pressure device, was not developed until over 100 years later, at the end of the 1800s. Iron lung use reached its zenith with the polio epidemic of the 1950's. Long-term respiratory centers came into existence for victims of the poliomyelitis epidemics of the 1940's and 1950's and by the end of the 1950's over 1000 polio survivors, requiring both partial and total ventilatory support, were living at home (Gillis, 1989; Gorski, 1996).

With advances in high altitude flying during World War II, researchers developed technology that resulted in the modern mechanical ventilator. Forrest M. Byrd designed

in-flight breathing devices that would lead the way to development of the BABYbird infant ventilator. Ultimately, this development resulted in a 60% reduction in infant mortality associated with Infant Respiratory Distress Syndrome. Further advances in the 1970s and 1980s led to the development of sophisticated devices, including computer enhanced mechanical ventilation, that further improved the long-term survival of children with various respiratory problems. High frequency jet ventilation and artificial surfactant are assisting the smallest premature infants to survive. Non-invasive ventilation (BI-Pap) is now being used side-by-side with invasive ventilation. Liquid ventilation is moving from the experimental laboratory into the patient care realm (Lemburg, 2000; Rhoades, 2001).

Literature concerning ventilator dependent children began to emerge in various sources in the 1980s. In 1984, Lawrence wrote that home care for ventilator-dependent children provided them with a chance to live a normal life as she reported on one of the earliest home ventilator programs. In this program, established at Johns Hopkins Hospital, specific children were identified as candidates for home care. Parent providers were given substantial teaching and allowed gradually to assume responsibility for the care of the child before they were discharged from intensive care units. A study reported in 1985 reviewed the outcome of home mechanical ventilation with 54 children over 20 years. This study determined that “although home ventilation of ventilator-dependent children involves certain risks and expenses, we have been impressed that a home

program has been physically, financially and emotionally beneficial to the majority of patients and families” (Frates, Splaingard, Smith & Harrison, 1991).

The true demography of ventilator dependent children is unknown. However, one can extrapolate much about the demographic characteristics of this special group from a 1996 study. Between 1978 and 1993, eighty-nine patients were assisted through the Mechanical Home Ventilation program through the University of Michigan’s Pediatric and Adolescent Services. The thirty-one females and fifty-eight males had been home a mean of 3.3 years at the time of the study. Of the total, twelve had died, four had been weaned from the ventilator and five had been lost to follow-up, leaving sixty-eight for data collection in the study. The diagnostic group with the greatest number of subjects was spinal cord injury (34%) followed by myopathies (21%), bronchopulmonary dysplasia (8%) and hypoventilation syndrome (7%). Neuromuscular dysfunction accounted for 70% of the mechanical ventilation requirements. The average age for initiation of mechanical ventilation was 7.2 years. The majority of patients (73%) were discharged from a pediatric rehabilitation center, which in this study was found to be a component of successful home care (Nelson, Carroll, Hurvitz & Dean, 1996).

In spite of early and ongoing encouragement to place such children at home, various obstacles have been identified that prevent timely discharge to home for ventilator dependent children. DeWitt, Jansen, Ward and Keens (1993) noted that ventilator dependent children often remained hospitalized for non-medical reasons. Specifically, they found the greatest obstacle to discharge was acquiring funding for

home care and arranging out of home placement for children who could not return to their immediate families. In their report, public funding took much longer to acquire than that which came from private agencies.

In spite of various barriers, ventilator-dependent children and youths do go home and this challenges resources in the family and the community. Careful discharge planning and follow-up is imperative to successful reintegrating of ventilator-dependent youths (Miller, Steele, Nadell, Tilton & Gates, 1993). Numerous authors describe successful discharge programs for the children and their families (Capen & Dedlow, 1998; Corbett, 1998; McCarthy, 1986; Posch & Edwards, 1988; Schreiner, Donar & Kettrick, 1987; Schraeder, 1979).

Continuing the education of children who are ventilator dependent has been a challenge in every situation. Federal law requires that education continue in the least restrictive environment. Thus, placements for all ventilator-dependent children should be continued in the public school systems of their home communities, although attitudinal not technical barriers prevent successful integration of children into school-based programs (Jones, Chatterbuck, Marquis, Turnbull, & Moberly, (1996).

Children who are ventilator dependent have been living at home for some time now. Home care resources are in place, yet funding is difficult to secure. Educational opportunities are legislated and are available, but attitudes within the schools create barriers for these children. Discharge programs were identified as key to success for the child and the family at home.

Summary

The population studied has been demographically identified and definitions have been provided of the child who requires life-sustaining assistive technology (Andrews & Nielsen, 1988; Burr et al., 1983; Gillis et al., 1989; Hill, 1993; Mausner, 1995; Newacheck, 1989; OTA, 1987). Parents have been described as competent to provide care for technology-dependent children and seem to prefer caring for their own children at home (Fields, Coble, Pollack and Kaufman, 1991; Teague et al. 1994). Stresses associated with caring for children who require life-sustaining assistive technology have been identified, which may be alleviated by the use of such community-based resources as respite care. Family-centered care has been shown to support the inclusion of the family in the assessment of care needs for technology dependent children as well as in the planning, interventions and evaluation of care (Ahmann, 1994; Patterson, Jernell, Leonard & Titus, 1994; Petr, Murdock & Chapin, 1995; Smith, 1991; Stevens, 1991; Stoller & Pugliese, 1989). Home care has been generally demonstrated to be most cost-effective (Burr, Guyer, Todres, Abrahams & Chiodo, 1983; Fields, Coble, Pollack, & Kaufman, 1991) and as developmentally efficacious and beneficial for children (Ahmann & Lipsi, 1991; Fulcher, 1988; Kohrman, 1994; McCarthy, 1986; Schreiner, Donar & Ketterick, 1987; Stutts, 1994; Yoos, 1988). Ethical questions have been considered (Arras, Dubler & Neveloff, 1994). Despite the volume of literature that demonstrates a growing understanding on technology dependent children (Newacheck, 1989), an

ongoing research agenda regarding various aspects of care for these children, and much information about, specifically, ventilator-dependent children in their homes, there continues to be little or no evidence of research describing the lived experience of the children who require life-sustaining assistive technology. Specifically nothing is known of the experience of the child who is ventilator-dependent. Therefore, review of the extant literature indicates the need for further study.

CHAPTER 3

METHODOLOGY

The purpose of this study was to explore and describe the experience ventilator-dependent children. A phenomenological interview design and interpretational procedure was used to discover the thematic structure of the relevant experiences for the present set of participants. This chapter reviews the underlying assumptions and characteristics of existential phenomenological method selected for use in this study. In this chapter, the role of the researcher, data collection and recording procedures, steps for human subjects (participant) protection, and the process of data analysis will be discussed. Finally, issues of rigor and credibility will be addressed.

Existential Phenomenological Approach

Existential phenomenology is at once both a philosophy and methodology that seeks to describe the living experiences of people. Phenomenological researchers make an effort to describe such experience according to the persons who have intimate understanding of them and in doing so generate understanding while providing insight and generating potential for further research.

In this study, existential phenomenological methodology was used to render a description of the experience of living with a ventilator as experienced by children. This

method, described by Spiegleberg (1965), has the primary objective of “direct investigation and description of phenomena as consciously experienced... as free as possible from unexplained preconceptions and presuppositions” (p.3). Further, phenomenology can be characterized as a way of viewing everything with which one comes in contact. Thus, “it is the lived experience that presents to the individual what is true or real in his or her life” (Streubert & Carpenter, 1999, p. 44) with the aim “to produce clear and accurate descriptions of a particular aspect of human experience” (Polkinghorne, 1989, p. 44). Existential-phenomenological research produces “a rigorous description of human life as it is lived and reflected upon in all of its first person concreteness, urgency and ambiguity. For existential-phenomenology the world is to be lived and described, not explained” (Pollio, Henley & Thompson, 1997, pp. 12-13).

Existential phenomenological method requires the use of a phenomenological interview. Preparation for the interviewing comes as the interviewer brackets, with an expert in the method, preconceived notions regarding the phenomenon of interest. During a bracketing interview, the researcher is asked (by the aforementioned expert in the method) to respond to the same question that will be asked by the researcher of the participants in the study. As the interview progresses, preconceived notions and possible biases are elucidated for the researcher.

Although still controversial among qualitative researchers, bracketing is believed to remove constraints from the interview process that would inadvertently lead the participants away from their true experience. Thus, the interviewer and the participant

would attain “a rigorous and significant description of the world of everyday human experience as it is lived and described” (Pollio, Henley & Thompson, 1997, p. 28). The expected outcome of this research is the explication of a thematic patterning and comprehensive description of the lived experience of the child who is ventilator-dependent.

Existential-phenomenology is an appropriate research methodology for use with children. Phenomenological interviewing gives the participant an opportunity to tell a very personal story about a particular experience of which he or she has knowledge. As noted in Chapter 1, children like to tell stories. “Children tell stories to organize their experience and their knowledge and to communicate that knowledge to others... stories not only reconstruct experience and communicate experience, they are experience... through the stories we tell about ourselves, we construct ourselves” (Engle, 1995, pp. 54-55).

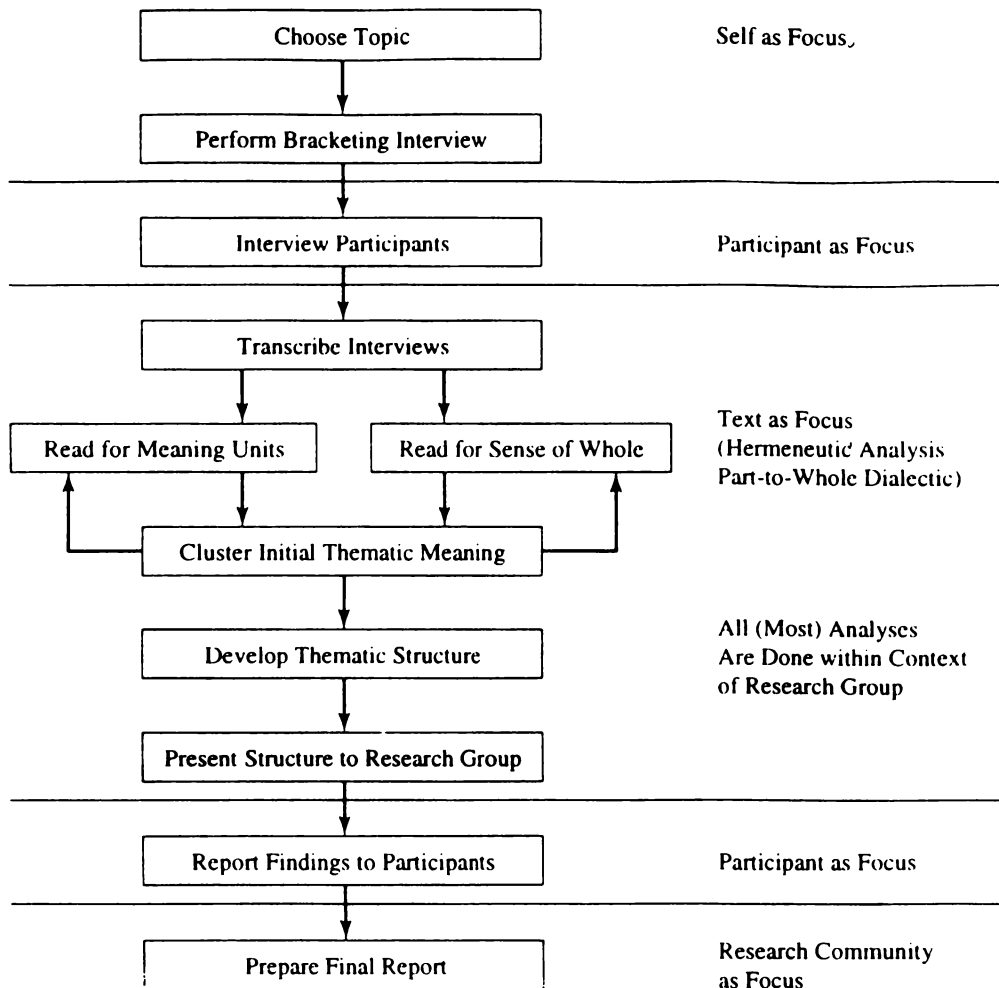
A rigorous phenomenological methodology has been described by Pollio, Henley and Thompson (1997). This methodology uses the phenomenological interview as the basic data gathering procedure. Utilizing dialogue, the investigator “assumes a respectful position vis-à-vis the real expert, the subject, or more appropriately the co-researcher” (p.29). Thus, the researcher encourages a full explication of the experience by the person having had the relevant experience of phenomenon. Data are collected by audio-taping interviews with research participants. Interviews are transcribed verbatim and on analysis yield thorough descriptions of the human experience of interest. Pollio, Henley and

Thompson affirm that this methodology is most appropriate for the researcher who seeks to fully describe the human experience of interest.

Figure 3.1 provides a diagrammatic depiction of the process utilized in a phenomenological research project (see Figure 3.1). Once a topic is determined and at a time preceding the interview of the research participants, a bracketing interview is undertaken by the researcher. This interview enables the researcher to identify any preconceived notions about the participants and become sensitive to biases that might be operating during the interviews. The researcher is allowed to in part experience the interview process to provide data that yield a thematic description of his/her current understanding of experiences with the phenomenon of interest.

Interviews with research participants often begin with a minimal number of specific questions from which the researcher derives demographic information. This is followed by a broad opening question asking the participant to describe the experience of interest in detail. Further questioning and comments by the researcher are for the purpose of encouraging the participant and to facilitate a full description of the experience of interest.

All interviews are audio-taped and subsequently transcribed verbatim to create a written text for purposes of analysis. Texts of all interviews are read for a sense of the whole. Transcripts are re-read for meaning units. Meaning units are clustered using a hermeneutic analysis. From this analysis a thematic structure is derived. Analysis is done both independently by the researcher and within a research group for added benefit



Source: Pollio, H. R., Henley, T. & Thompson, C. B. (1997). The phenomenology of everyday life. Cambridge, United Kingdom: Cambridge University Press.

of different perspectives. When a thematic structure was described, the findings are reported to study participants for their response and revision as necessary. In concluding the study, a report of the research is disseminated (Pollio, Henley & Thompson, 1997; Thomas & Pollio, 2002).

Sampling Plan and Participant Recruitment

Sampling Plan

Purposive sampling was utilized for this research study. This method of sampling selects participants based on their experience with the phenomena of interest (Streubert & Carpenter, 1999), that of being ventilator dependent. The sampling procedure used networking via word-of-mouth and snowballing techniques. The sample for the study included nine children between the ages of seven and twelve years of age who required ventilator support for part or all of each day. This sample was derived from the population of American children who are dependent on life-sustaining assistive technology.

Calls for participants were made in the community of caregivers with whom the researcher was familiar. Physicians and home health agencies that provided service to proposed participants were identified. This mechanism was proposed by physicians and home care service providers as being the most effective mechanism for identifying potential participants. Information regarding the study and human subjects protection was then faxed to each physician and home care agency involved, who in turn contacted

parents of possible participants. As participants were identified and consent obtained from the parents for contact to be made, the researcher contacted the parent by telephone to further explain the study and seek final approval for his or her child to participate. Once approval was gained, the researcher secured a time and location for the interview to take place and mailed to the parent(s) and the participant a packet of information (Appendix A) including the written invitation for the child to participate in the study, informed consent information, and child assent information. Nine children participated.

A call to the parent and the participant was made one to two days prior to the scheduled appointment to ensure that timing was still acceptable for the interview. One interview had to be rescheduled due to interviewer illness and one had to be re-scheduled because of travel constraints. No interviews had to be rescheduled because of illness on the part of the child. Data were collected during one interview encounter with each child-participant.

Participant Inclusion Requirements

Individuals included in this study were between seven and twelve years of age and were cognitively appropriate for their age according to parental report. Ventilator dependence ranged from eight to twenty-four hours per day and all children lived at home with parents (biological and adoptive) and siblings. All children communicated verbally with the researcher and gave assent to participate and be tape-recorded during the interview.

Human Subjects Protection

Human subject protection was afforded participants in compliance with the University of Tennessee requirements for human subjects research with special consideration given to these research participants because of their status as children. Approval was obtained prior to the beginning of the study from the University of Tennessee College of Nursing Human Subjects Review Committee (Appendix A) and from the University of Tennessee Institutional Review Board. Before interviewing, each participant and their parent was identified and informed orally of the purpose of the study. An invitation to participate was extended on behalf of the researcher by a care-or-service provider to the child. The parents had the opportunity to decline the invitation before the children ever had knowledge of the invitation or the researcher had knowledge of the specific children. The researcher then initiated contact with the parents. Parents who agreed to the participation of their child so indicated their willingness verbally to the researcher and further indicated their consent in allowing the researcher access to their home and child. Informed consent was obtained from the children subsequent to parental permission. Each participant received a copy of the information and consent form (Appendix B and C); confidentiality was maintained on all documents.

All consent forms, audiotapes, and typed transcripts are presently maintained and secured by the researcher. Participants had the opportunity to terminate an interview and/or withdraw from the study as they chose and at any time. None of the participants made the decision to withdraw from the study.

The very nature of phenomenology required in-depth audio-taped interviews and presented the researcher with opportunity for several special ethical considerations. Interviews are unpredictable and there was no way to be absolutely certain of what might be revealed during the interview. The risk of harm to the participants was considered minimal, however, and was not considered to be any greater than that which would normally occur in daily life. Additionally, the researcher has numerous years of experience with children who have special needs and was prepared to stop the interview and intervene should the child become physically or emotionally distressed by terminating the interview and responding to the child's immediate need. Parents or nurses remained in close proximity to the child at all times during the interviews in the event of physical or emotional distress. Finally, a clinical psychologist agreed to serve as a referral source should any concern arise with regard to the children or concerning the information obtained in the interviews. There was no apparent harm to any of the participants and the services of the clinical psychologist were not utilized. One child did indicate that he was tired at the conclusion of the interview.

Confidentiality was preserved during data collection, analysis and dissemination of findings. The researcher was the sole interviewer. A paid research assistant completed all verbatim transcriptions subsequent to signing a written statement guaranteeing her agreement to maintain participant confidentiality. The researcher maintains audiotapes and transcriptions in a secure location in her home and will preserve the data for a time of five years after which they will be destroyed. All interviews were coded alphabetically to

reflect the order of the interview in the data collection process. Names were changed to accommodate the order of data collection and participants are identified only by pseudonyms. Some of the interviews have been reviewed by members of the Phenomenology Research Group in the College of Nursing, University of Tennessee, Knoxville under the direction of Drs. Howard Pollio and Sandra Thomas. All participants in the analysis of the data signed confidentiality agreements prior to accessing the data and are expected to maintain confidentiality of the process. Group members have no knowledge of the actual identity of any participant.

Procedures for Data Collection

Bracketing

Prior to interviewing participants, the researcher participated in a “bracketing” interview with an expert in phenomenological interviewing. The same interview question was used as was used in the subsequent interviews of children. The interview was transcribed and analyzed according to standard procedure. As was anticipated, the bracketing interview revealed to the researcher an anticipated bias that the children would not be negatively affected by their experiences. The researcher gained insight regarding her attitudes and biases about children living with a ventilator. In particular, the bracketing experience revealed that the researcher had a preconceived expectation that the children would be able to accomplish anything they chose to accomplish. Also, the researcher expected the children to have or have access to all the resources they or their

families would need or want. Because of extensive familiarity with the literature about children who experienced adversity and their ability to be resilient, it was additionally believed that these special, ventilator dependent children would also demonstrate high level of resilience given their circumstance. This experience of bracketing was extremely useful in heightening the researcher's awareness of preconceived ideas about the experience allowing for enhanced openness to the experiences of the children interviewed.

Data Collection from Participants

Demographic Data

At the scheduled time of the interview, with the audiotape recording, each child was asked if he/she understood what was going to happen. Each child was then asked if he/she gave permission for the interview to proceed as well as permission for the audiotape recording of the interview. Initial casual conversation included inquiry about the child's age, school, pets, siblings, and chores. This format was followed to establish rapport and place the child at ease. Information about ventilatory devices used and underlying medical diagnoses was obtained from the parent(s) during initial phone calls. Gathering this information was necessary to establish the child's eligibility to be a participant in the study.

Phenomenological Interviewing

The phenomenological interview focuses directly on the experience of interest: in this case, the experience of the child who is ventilator-assisted. Thus, interview questions were unstructured and open ended. When the child appeared to be comfortable with the researcher, the child was asked the following: “Many people are interested in people like you who have _____ machine. What would you want to tell them about living with your machine?” Interviews lasted from thirty to seventy-five minutes.

Data Analysis

Phenomenologic data analysis requires that researchers “dwell with or become immersed in the data...to preserve the uniqueness of each participant’s lived experience while permitting understanding of the phenomenon under investigation’ (Streubert & Carpenter, 1999, p. 60). Interpretation of the interview data emerges subsequent to the original question asked of the participant. The expected outcome of this data analysis is to render a thematic patterning and comprehensive description of the lived experience of the child living with a machine.

Interpretation of Findings

Verbatim interview transcripts were analyzed in an interpretive manner through reading and discussion. During the interpretation an attempt was made to relate each portion of the text in relation to the whole of the text. Common elements of the

experience were sought and identified. Meaning units were clustered and themes emerged. Three transcripts were reviewed in total (or part) by members of the Phenomenology Research Group in the College of Nursing, University of Tennessee, Knoxville under the direction of Drs. Pollio and Thomas. Particular emphasis was given to the participant's developmental perspective when considering thematic patterns and ultimately the structure of an understanding of the experience of the child living with a ventilator.

Rigor and Credibility

“Rigor in qualitative research is demonstrated through researchers’ attention to and confirmation of information discovery” (Streubert & Carpenter, 1999, p. 28, 61). Threats to rigor may be related to procedural, ethical and analytical problems or concerns. Procedural rigor was assured by asking a question guided by suggestions of the research group and the dissertation advisor and committee. Procedural rigor was further assured by the researcher adhering to the procedure identified by the Pollio method, including the bracketing process, access to appropriate participants, and collecting sufficient data (Pollio, Henley & Thompson, 1997; Thomas & Pollio, 2002). Ethical rigor was assured by obtaining consent, protection of human rights, and informing participants of their rights. Adequate records of the data-collection process have been maintained in a thorough and confidential manner.

Credibility pertains to rigorous process and the believability of the findings as assured by the participants who experience the phenomenon of interest. In order to assure

credibility, rigorous procedure was adhered to by the researcher during data collection and in the research group during analysis of the transcripts. The researcher immersed herself in the data and grounding the analysis in interview text. At the completion of data analysis, the structure was presented to one research participant such that she could “clarify and re-shape the final thematic description” (Pollio, Henley and Thompson, 1997, pp. 59). She confirmed the description of the experience of living with ventilator. The confirmation by one or more participants of the accuracy of the thematic pattern of being ventilator-dependent authenticates the structure that has been derived as an outcome of phenomenological interview analysis. Thus, the findings are credible and dependable.

Summary

The experiences of children who are ventilator-dependent are absent in the existing literature. The purpose of this study was to describe the lived experience of the child who is ventilator-dependent. This chapter has included a discussion of the assumptions of qualitative research in general and, more specifically, of existential-phenomenologic research. Steps for human subjects (participant) protection have been described in compliance with the human subjects protection requirements of the University of Tennessee, Knoxville. Criteria for participant inclusion have been described. Procedures for data collection, data maintenance and data analysis have been

specified. Demonstration of rigor and credibility have been explicated. In the following chapter, the findings will be presented.

CHAPTER FOUR

RESULTS

This study investigated the experience of the child who is ventilator dependent. This method of philosophical inquiry and interviews provided me with rich data derived from verbatim transcriptions of unstructured interviews with nine children who are ventilator dependent. A thematic structure describing the experience of the research participants emerged as a result of interpretive analysis. As previously discussed, interviews with the children who agreed to participate were initiated with casual chatting about school, siblings, pets and usual chores to both establish rapport and obtain demographic data. Children were then asked to respond to the following question: “There are lots of people who are interested in people who have machines and devices like you do. What would you want them to know about your _____?” (In this opening question the specific ventilatory device was identified for each individual child.)

The description of each child’s experience was thematized using the methodology previously described. A thematic structure was developed as it emerged from the data. In this chapter, each child’s life circumstance will be described including demographic data. The thematic structure will then be presented and illustrated by samples of participant expression of each theme in verbatim quotations from the data.

Demographic Characteristics

The nine participants in this study ranged in age from seven to twelve years of age (mean 10.1 years) and were cognitively appropriate for age according to parent/caregiver report and verified during the interview. The children were from 4 states, two Midwestern and two southern. Two children were African-American, the remainder were Caucasian. There were four male participants and five female participants. All of the children interviewed lived in homes with one or two parents and siblings. The participants used various respiratory support devices. There were five children who required 24-hour-per-day mechanical ventilation; all of these children had permanent tracheostomies. One child required overnight mechanical ventilation and had a permanent tracheostomy. One child required periodic cuirasse vest treatment during the day and required portalung management overnight. One child required Bi-Pap management overnight. Lastly, one child who had a permanent tracheostomy, required continuous CPAP during the day and overnight ventilation. Some children required supplemental oxygen and others did not. The following section will introduce each individual participant and their unique circumstances. Names have been changed to protect the identity of the participants.

The Participants

Abby, interviewed in her bedroom at home, resides in a small house in a tiny lower-income rural community near a large Midwestern city. A levee overshadows the

dog-pens in the backyard, which is visible out her bedroom window. Over two hours from her primary providers, Abby has limb-girdle muscular dystrophy, is totally ventilator dependent and has both a bedside machine and a portable ventilator that remains attached to her electric wheelchair. Abby, who is ten years old, must go to the doctor via ambulance but wheels herself to school in her wheelchair. She has never been to the movies or a mall because the family lacks a vehicle that will accommodate her essential equipment. Abby has an older sister, a younger brother, and various pets. She lives with her parents who both work, has 10 hours-per-day nursing assistance and a full time educational assistant when she is in school. Abby loves Barbie, MTV, anything purple and stuffed animals. She visits with friends, helps her grandmother, who lives at the top of the hill, wears make-up and hates the color green. She argues with her mother about clothes and complains about her younger brother who annoys her. She plans to be a hairdresser when she grows up.

Billie, the youngest participant in the study, is seven years of age and has a bright engaging smile. He lives in an affluent neighborhood, on the outskirts of a large southern city. Born with achondroplasia (a type of dwarfism), Billie's cervical-neck defect has left him totally ventilator-dependent since infancy. He lives with both parents and a younger sibling who appeared to the researcher to be physically normal. He attends public school and has a full time education assistant in addition to 24-hour nursing attendance. Billie was interviewed in his well-equipped bedroom/den where all his family congregate. His electric wheelchair contains the portable ventilator that he uses continuously. Billie loves

Disney movies and being read to. His favorite toys are his trucks. He rolls around on the floor with his younger brother and watches to make sure that the toddler does not disconnect his machines.

Interviewed in her home in the downtown of a mid-sized city, Cassie lives in a middle class neighborhood with her mother and two older sisters. Cassie is African-American, ten years of age and has an undefined form of muscular dystrophy (as does one sister) that has caused severe scoliosis and muscular degeneration with progressive respiratory failure. Cassie uses BI-Pap during the overnight hours. Although Cassie continues to be enrolled in public school, her life threatening illnesses this past year have kept her home schooled through the public school system. She currently spends most of her time at home because she has outgrown her wheelchair and is no longer able to walk. Cassie anticipates spinal fusion surgery this fall and the outcomes are expected to include improved ventilatory status, at least for a while. An older sister, who has the same condition, is less severely affected but also requires BI-Pap and shares both a bedroom and a machine with Cassie. Cassie says that her BI-Pap is making her better and is quite clear that she will get better because she wishes it. She loves to have friends over, likes to shop, considers herself a “princess” and wants to go away to spend the night. Cassie has no nursing assistance. Her mother provides all her care, does not work outside the home, and has no resource for assistance in care giving to the girls in the area where they live. Cassie and her family anticipate moving to a larger mid-western city sometime this year so that Cassie’s affluent uncle can assist the family more effectively.

The home where David, eleven, was interviewed sits in the midst of a large open meadow, well back off the road, in a rural mountainous area. This beautiful, open, spacious home has been built because of David's special accommodation needs and is occupied by David, his younger brother and his mother. David, completely dependent on others for all his needs, sits in an electric wheelchair he controls with a mouth stick. David's mother home schools both children because of her strong religious beliefs and is the sole caregiver for David who has been a quadriplegic since an automobile accident when he was five years old. (His mother and brother had minor injuries in the accident.) Her only assistance comes from family and a few carefully selected family friends. David's father is not involved with the family. David loves to sit on the porch that is situated on all sides of the house and watch his grandfather mow the large grassy area surrounding the house. He likes going to his friend's house, loves the hamburgers his friend's father prepares and is trying to talk his mother into a chicken and rooster for pets.

Eddie resides in a bedroom community of a large northern metropolitan area. Living in a very affluent neighborhood, Eddie's interview took place in the wing of his home specially designed and equipped for him. As one enters from the computer/study area to the bedroom, it is apparent that Eddie has access to the very best medical equipment available along with video movies too numerous to count and the latest computer equipment. Eddie has 24-hour-per-day nursing care and attends public school. Eddie, severely debilitated by myotubular myopathy, has very limited physical function. He has limited upper extremity function and his lower extremities are braced. He requires

continuous constant positive airway pressure (CPAP) during the day and is ventilator dependent overnight. Eddie likes to collect movies, go to baseball games, play video games and loves to make and spend money. Eddie has two older brothers and a pet golden retriever and often spends the night at his grandmother's house.

Frances, who resides in a large mid-western city, lives in a traditional house, situated up a narrow, steeply inclined driveway on a busy thoroughfare. Entering the house one is immediately in the small living room dominated by numerous family pictures, religious icons and Frances in her wheelchair. Moving into the kitchen, one can see out the window the extensive deck recently completed for Frances by her father. Frances is profoundly disabled by her spinal muscular atrophy and appears significantly disfigured from the shoulders down. Frances, in seventh grade and twelve years old, is the oldest of the participants and looks forward to her thirteenth birthday. She has bright brown eyes, a winning smile and seems somewhat embarrassed by the attention being paid to her. Frances has some nursing care, but her mother reports that the care received is quite limited due to the unavailability of nurses in her community. Frances attends public school, with an education assistant, and has just gotten her first electric wheelchair. Frances attended camp this summer and, as she awaits the opening of school this fall, spends much time on her computer in her upstairs bedroom and thinks parents just do not know what fun is all about.

Georgie lives in a large mobile home located in a mobile home community near a small rural southern town. Entering the home, one is impressed by the giant screen

television dominating the living room. One small child sleeps on the sofa, another comes to the door with Georgie's mother. Georgie appears from the hall behind the kitchen that is located to the back left of the living room. Georgie is quadriplegic and totally ventilator dependent since an accident when he was five. At that time he was riding on a four-wheeler with his father. When they hit an unexpected hole on the path they were riding on, Georgie was thrown-off and was hit by a car (driven by a family member) following them. The neck fracture he sustained left him in his current condition. His mother reports they are currently awaiting an appointment for surgery to insert a phrenic nerve pacemaker that will allow Georgie more freedom and decrease his ventilator dependence. Georgie, ten years of age, also has a bright, lopsided smile. He loves to tell jokes, is a stickler for detail, is a sports fanatic and gets in trouble for cussing and knocking holes in the walls with his wheelchair. He has nursing care during the day so his mother can work, attends public school with his nurse accompanying him and loves his little sisters. Georgie kissed the researcher on the cheek as she left and said his only regret was that he could not give a hug, too.

Helen is a twelve-year-old African American child who resides in a bedroom community of a large southern city. Her mother, a widow for the past five years, is raising Helen and her two older brothers alone. Helen's father, who suffered from congenital heart disease, was the primary caregiver for all the children until his death. Helen's mother works full time and depends on her children to care for each other and themselves when she is not at home. Helen has chronic hypoventilation syndrome and is

a Sudden Infant Death Syndrome survivor. She has a permanent tracheostomy and is ventilator dependent at night. Helen manages her ventilator independently and is ready to demonstrate her skills to anyone who is curious. Helen loves to swim, go to church and play with friends. She does well in school and is rapidly catching up to her expected grade level after being moved out of the unnecessary special education classes in which she had been placed by the school system. Helen had to be retrieved from a church activity for her interview. She is bright and engaging, arguing readily with her mother when told she needs a bath before bed.

Lastly, Lori is a ten-year-old child who has Congenital Chronic Hypoventilation Syndrome who is described by her mother as a Sudden Infant Death Syndrome survivor. She and her older sister are adopted. Her sister, who also experiences this rare disorder, is seriously debilitated because of chronic hypoxia since refusing supplemental ventilatory support several years ago. Lori lives in a tiny, middle class bedroom community of a major midwestern city. Her family home is in marked disrepair. The front door opens into a living room dominated by barking dogs. The 'L' shaped room has at the left hand end a dining table covered with the remains of an afternoon cookout. The furniture in the room borders the periphery leaving space for the two dog kennels and the wheelchairs and other equipment Lori and her sister require. There is little room for anything else. The kitchen is crowded and the hallways used for storage. Lori's bedroom, shared with her sister, has a dresser, a single bed, bookcases for belongings and the portalung in which Lori sleeps. Covered with Winnie the Pooh stickers, the device, nevertheless, bears an all

too striking resemblance to the iron lungs of days gone by. She uses a cuirass vest during the day. In addition to her sister, Lori lives with an older brother, who is physically normal, and both parents. Her father, a warehouseman, suffers from mental health concerns and her mother is employed full time for a regional university. Lori loves going to church, playing by herself and spending time with friends. She is looking forward to being home schooled as the school she attends is not supportive of her physical needs. Lori needs a wheelchair if outside of the home. Her condition is progressive.

Thematic Structure

The experience of the child who is ventilator dependent was described by participants as being contextualized by Others (both other people who give care and machines that sustain life), thus the child experiences never being alone. Time was not an especially relevant context for this experience. The central strand of the experience was the emphatic affirmation: I'm still am a person! Two other themes emerged in concert with this concept of personal self. Can/Can't expresses the opportunities to be taken advantage of (Can) and the opportunities that require some modification to accomplish (Can't). Normal/Different is an expression of the child's experience with others outside of the care giving relationship. Being Normal results in no special or peculiar reaction from individuals outside the care giving realm. Being Different causes some people to act in insensitive ways. Each of the themes are interrelated and interwoven, while being imposed upon the grounds of the Other (human and machine) and never being alone. A

schematic depiction of the experience and the interrelationships of the three themes as grounded against the domain of Other is presented in Figure 4.1. The interpretation of this schematic is discussed in the next section; following is a discussion of individual themes.

Diagram of the Experience

Figure 4.1 is a schematic representation of the experience of the child who is ventilator dependent. The circles representing the Other and Never Being Alone define the context of the experience as described by the children. The circles overlap to create the personal world of the participants. The dominant theme, **I'm still a person!** is represented as a diamond that denotes the unique and precious quality of each child. The statement is located above and outside the diamond to depict the emphasis on the whole experience of this concept of the self. The theme **Can/Can't** is expressed in the locating of **Can** at the apex and oppositional to **Can't** at the bottom point. Can/Can't are understood as being related to ability. **Normal** at the left side of the diamond is on a continuum with **Different** located at the right side of the diamond and does not necessarily represent the opposite of Normal. The theme Normal/Different refers to the experience of the child with regard to the response he or she receives from non-care-giving others in the environment. Thus, when the child experiences Normal, the response of the non-care-giving other is rather neutral. However, should the child experience Different, the non-care-giving other may respond in a manner demeaning to the child.

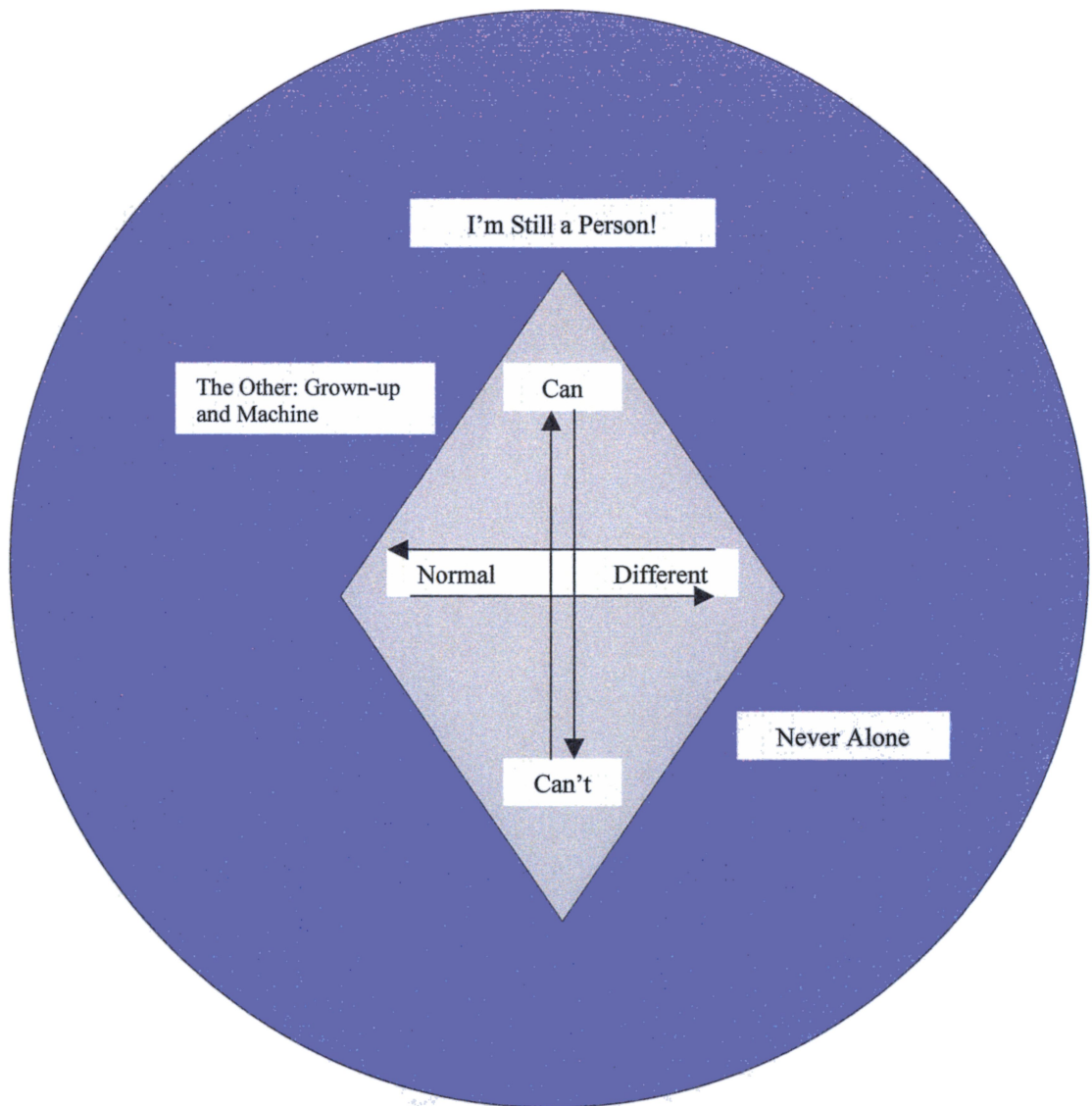


Figure 4.1. Thematic Structure:
The Experience of the Child who is Ventilator Dependent

The interrelatedness and interweaving of themes is noted in the parallel opposing arrows. All lines cross all lines and any shift in one effectively shifts the other. Thus, for example, a movement toward Can could vary either Normal or Different while still maintaining I'm still a person! Conversely, as the experience becomes one in which Can't is figural, I'm a person! is maintained within the continuum of Normal/Different.

Contextual Grounds for the Experience

The Other

All life is describe in the context of others. From birth, the human infant is dependent upon the Other, usually the biologic or adoptive parent, to provide the environment and the nurturance essential for the sustenance of life. Nurturance from the Other includes providing for nourishment and hygiene, and protection from infection and environmental threats. As the infant develops in childhood and on toward adulthood, the Other assumes a different significance and particular identities other than mother or father. For example, the Other is essential for relationships. Relationships for a child include those with playmates, friends, schoolmates, teachers, ministers, etc. Ultimately, the child grows and develops, and in doing so progresses through childhood to adolescence and adulthood. As this occurs, the other person in the relational dyad is often a person other than the parent.

The Other is delimited in the experience of the child who is ventilator dependent, specifically that of a *human caregiver-other* and also that of a *mechanical-other*. The

human caregiver-other may include mother, father, sibling, nurse, friend or any person who supports the nurturance of the child. The mechanical other is essential in some capacity for life and includes the various mechanical devices the child may use: the ventilator, Bi-Pap, CPAP or portalung. It is in this duo of the Other that the experience of the child who is ventilator dependent is contextually grounded. The human caregiver continues indefinitely as the provider of nurturance yet there is little developmental evolution in the relationship. The mechanical-other also sustains the child. The human caregiver-other protects the child from environmental threats; the mechanical-other provides support for life to continue.

All participants gave extensive descriptions of how their various machines operated, what was necessary to keep them functioning, and their various maintenance requirements. All participants in this study were clear in their understanding of and experience with their particular machines, the mechanical-other. One child summed up just exactly what the ventilator did as he described what the mechanical-other accomplished for him. He said:

“It just helps breathe air into me and I don’t breathe on my own, so it does the breathing for me.”

Another child, related her experience with forgetting she had any particular machine:

“Sometimes you forget you have it. It is like, a breathing machine... It gives me air... It helps me breathe when I can’t... It is just there. I take it everywhere I go.”

Another child knew that the machine was beneficial to her health. When questioned about her revelation about the necessity of the machine for her well-being she said:

“It helps me breathe...And I need it. It helps me...(How do you know it helps?)

Because my head doesn’t hurt any more and the doctors tell me.”

Another child, very positive about the experience with the machine, said:

“It’s really cool, it makes me breathe better; it helps the body; it helps the mind; It also keeps you strong; it helps your muscles grow; it makes me talk; it is just a machine that helps me; when I am off from it, I can’t breathe and (my) lungs stop”

Some children require intermittent mechanical ventilation. This may amount to time during the day on a particular device, time on that same or another device overnight, or both. There was an understanding for this child not only about her need for the mechanical Other but also about the ramifications of not having the machine. She reported:

”It gives me more breaths when I go to sleep. It gives me more breaths. (pause)

Without it...it helps give me more breaths than I’m ‘spose [sic] to have. And then it helps me breathe more regularly at night when I go to sleep and gives me more breaths. (pause) Like when I go to sleep I stop breathing, it gives me my breaths so I can breathe.”

The same child expressed what the potential outcome for her might be without the machine and related:

“If you go to sleep and stop breathing, it can completely mess up your life. You could pass away. (pause) You could just go to sleep and never wake up again.”

Participants all described the grown-ups in their lives in some manner. Some were very explicit about what the grown-up meant to them and what their experience was like with them. The following comment reflects various grown-up others and expresses the child’s resentfulness of this intrusion by grown-up others:

“Most of the time I am surrounded by all these people who are doctors and nurses and Mom asking questions like, ‘Are you ok?’ (pause) I really don’t like that, I like to be alone.”

Another participant was more positive about the others constantly in her world; those included both mother and friends:

“I do everything, do all kinds of stuff. Sometimes I have to do stuff with my mom. Sometimes I just do stuff with my friends.”

The experience the child had with a human caregiver-other was often enmeshed with the experience with the mechanical-other such that one did not exist without the other. One child related the following about the mechanical-other first and then the human caregiver-other and then the two in collaboration: the machine and the person she expected to need:

“It’s just there. I take it everywhere I go. I have the kind that goes on a battery and you can go outside and have a normal life, sort of.... But you always have to have a nurse around, or your mother, or your father, or always a grownup. I can’t go

outside by myself because I can come apart. I can put it back together, but the ventilator will let me know when it comes apart and I always have to have a nurse or my mom or dad, or just a grownup, to go anywhere. I can't go anywhere by myself."

Another child spoke of the interrelationship of human caregiver and the mechanical-other as he described the beeping ventilator alarm that alerts the human caregiver to the machine:

[Tell me about beeping. What is beeping? Is it like an alarm?] "Yeah, an alarm for when it pops off [Referring to disconnection]. After a few breaths, like if they are not in the room, they can hear it, they will know they can come back and put me back on."

This same child who had a life-threatening event when the ventilator became disconnected tells us the story of that event. He was not heard as he struggled and is aware that such events could cause him to die. He further reported:

"One night I was lying on my stomach...."(it became disconnected)" Nobody knew except me...I was yelling and nobody heard me....it felt like I was going to die...When it is off (the ventilator) I can't talk at all...Like if somebody is not in the room with me, they probably won't hear me unless the vent beep. "(referring again to the disconnection)," I wasn't asleep when it happened, um, I just want to get it back on. I don't want to suffocate."

Thus, the experience of the child who is ventilator-dependent is contextualized by a human and mechanical other. Both of these “others” nurture the child and protect the child from threats in his or her environment. Further contextualizing this experience is the ground of never being alone which in concert with the Other provides the comprehensive ground for this experience.

Never Being Alone

The ventilator-dependent child’s experience is also one of Never Being Alone. To stay alive, the child must remain constantly in the presence of the human other-other and/or the mechanical-other. (Indeed, during all the interviews with the participants, a primary caregiver for the child was no further than the next room away. In some cases, the caregiver remained in the same room, present at all times, yet out of the visual field of the participant). The condition of the child requires the presence of one or both of the Others at all times, whether or not the child requests such attendance. This experience of never being alone is matter-of-factly acknowledged and accepted by all the participants. One child said:

“It’s pretty good because I can’t reach anything or do anything (by myself or unassisted)...”

Another reported on the constant vigil kept by the human other:

“Some of the nurses, (pause) sometimes they are afraid I might stop breathing, so they watch me all the time...”

Some children reported experiencing constraint by the omnipresent other and express this in complaints about the restrictions placed on their activities. An example is found in one child's longing to spend the night away from her home:

"I don't think I like it...Because I want to go places and spend all night...(How does it make you feel?) Mad...Because when I really, really want to go somewhere, I can't...I go ask Mommy...She says 'no!' I says please and she says, 'Nope, because you have the breathing machine.' And I say, Ohhh... (shrug) I just don't go. (pause) I stay home!"

Another child finds the converse in not being allowed to have others spend the night with him. Another speaks longingly of expeditions with friends:

"But most of the other girls my age can go with their friends alone out to a movie or to the park. Most of them go to the park or to the shopping center down the street and I have to go with one of my nurses."

The same child further yearns to be alone:

"Most of the time I am surrounded by all these people who are doctors and nurses and Mom asking questions like, "Are you OK?"; I don't really like that, I like to be alone."

This child goes on to say that while being alone, she would play with her dolls, write in her diary, pray or plan for the next day. Another child notes:

"But you always have to have a nurse around, or your mother, or your father, or always a grown-up. I can't go outside by myself because I can come apart. I can

put it back together, but the ventilator will let me know when it comes apart and I always have to have a nurse or my mom or my dad, or just a grown-up to go anywhere. I can't go anywhere by myself."

Still another child expresses the desire to not have her caregiver constantly present when she talks about her recent trip to a special camp for children who have various ventilatory challenges:

(on being at camp) "They (counselors and caregivers) are not like a parent hovering over your shoulder watching everything you do, just let you have a free and fun weekend. They are really cool. They (parents) don't know the definition of fun!

To summarize, the experience of the child who is ventilator dependent is grounded in the context of never being alone. It is the omnipresent other, either the human other or the mechanical-other, that constructs the context within which the child lives. There must be the machine. There must be a human caregiver. They must be present. Only with someone present is there a sense of safety from the environmental threat of disconnection or dysfunction that challenges the existence of the child. Yet constantly being in the presence of the other hampers the life of the child. This is true in the experience of one child who suggested that:

[Being on the vent] "Well, it makes me feel pretty sad. It makes me feel like some kind of dog, chained dog out in the front yard. ...I can't spend the night out

anywhere and nobody can spend the night here like my friends, so it is kind of depressing for me. Makes me sad.”

Themes

The experience of the child who is ventilator dependent has been discussed within a contextual ground of the Other and Never Being Alone. Within this context, three themes stand out as distinctive: a concern with a sense of the unique self: I’m still a person!; a concern with ability: Can/Can’t; and an acknowledgement of the encounters that the child has with non-care-giving others: Normal/Different.

I’m Still a Person!

The child’s experience was described as figural based his or her intense awareness of his or her place in the world. Ventilator-dependent children are observant of how others outside the caregiving relationship respond to them. This acute awareness makes their interpretation of the behaviors of others notable in their experiences as persons. The awareness they have of themselves is introduced and then clarified, by the assumptions of non-care-giving others about them, their ventilator devices, and what they are able or not able to accomplish. One child reported that she had been looked at by schoolmates as ‘weird.’ Another child asked the researcher if there were other children like him, connected to ventilators and totally dependent on the care of others. Another perceived that because she had a particular disease, others thought her retarded and unable to answer questions about her condition. Thus it is with emphasis one child said:

“I’m still a person. There is nothing wrong with me. I’m normal, it’s just I have a tube in my throat and a ventilator and I’m in a wheelchair that moves!”

The children demonstrated self-confidence in themselves and appreciation for life, regardless of the constraints they might have to deal with. This child spoke about the responsibility of the non-care-giving others to accept her as they interacted with her and any other child or adult who had special circumstances:

“Your ventilator is what is there for breathing and people should just accept it; just accept people. And it isn’t just about people with ventilators, it’s anybody with a disability...it is important to forget the chair is there and remember that the person is there so that you can be there for each other.”

Another child, who spent much of the interview telling jokes he concocted, seemingly certain they were funny, was very articulate about himself and fiery as he reported about his cognitive ability,

“I know (about my ventilator); I ain’t stupid. I’ve got a brain (laugh).”

He also said regarding being accepted by non-care-giving others:

“If you don’t like me, don’t make fun of me. Just don’t say anything!”

All of the children articulated an awareness of themselves, and their role in their family. One child expressed what she expected to do as a grown up. They spoke knowledgeably about their needs:

“If you have it on, don’t turn it off...Take it off, then turn it off.”

Another child reported her exasperation with being overlooked, especially in the hospital environment, and because of her physical condition:

“Some of the doctors treated me like I’m little and don’t understand them, but I can...Most little kids, when they come to the hospital they ask them regular grown-up questions, but then they hear I have this disease and then they think. ‘Oh she probably can’t think right.’ So they ask me those dumb kinds of questions.”

She went on to say that when questioned by her friends she had to use various explanations for them to understand:

“A few of my old friends, they have asked me questions about it (ventilatory device) and they would just say. ‘uh-huh’ and they made me tell it over and over because they couldn’t get it. And then I had to break it down even more so that they would get it instead of using big words like ventilator, they would go, ‘What’s that?.’ And I told them about _____ and stuff... It feels good [to have to explain things] actually because I know something better than they do.”

The children were articulate and dignified as they spoke of their machines and caregivers, likes and dislikes, family, friends, pets, siblings and school. They spoke of where they traveled and what they did when they arrived. They acknowledged their limitations and what they could do to confront their limitations. It is this knowledge that

drew attention to a second theme, “Can/Can’t” that further reveals the experience of the child who is ventilator dependent.

Can/Can’t

The experience of the child who is ventilator dependent is often described in terms of what can be accomplished and what cannot be accomplished. Can gives rise to having resources, ability, and opportunity. Can’t, to the contrary, depicts the absence or unavailability of resources, ability and opportunity. One child speaks of restrictions to her activities but at the same time is emphatic about what she is able to accomplish. Clearly that which is not available to this child is of less significance.

“Like me, I can’t walk, but I have not been able to do that for a while. In my case, I can do different things...I can’t go and do normal things, like normal kids...like get up and run and play on the monkey bars. But that doesn’t matter to me. I generally run around in my wheel chair...and play in the yard.”

Another child demonstrates creative critical problem solving as he/she related that if you cannot accomplish something in one manner, do it in another:

“You can do whatever you want, you just have to put your mind to it and then you can do it. And if physically you can’t do something, you may not be able to do it that way, the way everybody else does it, but maybe you can do it in a different way.”

Another child recognized that while she experiences limitations in what she could do occasionally, it was just a matter of course to find a way around the obstacle. She

expressed that she had the resources to think through the problem and achieve success in another manner:

“You just don’t worry about what you can’t do, you just do what you can do and worry about the stuff you can’t do later and think of some way to do the thing that you can’t do now, so you may be able to do it later.”

She also said that having the ventilator gave her possibilities that she would not otherwise have because of her physical limitations:

(The ventilator gives you possibilities) “Possibility is just to grab them because you might not be able to do them again because something might happen or anything. Just do them. Don’t pass up the opportunity. Just do it. I do everything, do all kinds of stuff...I just think of ways to rig up stuff so that I can do stuff that everybody else is doing.”

Another child spoke of the things that she can do that are similar to what other children can do:

“I can move around; I can play in the floor with the dogs; I can sit and watch TV; I can draw at the table; And I could even, if I wanted to, get up and stretch my arms.”

Few participants spoke specifically of Can’t. It was implied by what Can allowed for them. One child did speak about what Can’t meant to her and how she accommodated for that experience with substitution of another:

“I didn’t get to go on many of the rides (in Disney World)...there aren’t many I can go on because I’m in a wheelchair. I’d rather buy things.”

She also reported her feelings related to a younger sibling who had normal function:

“My 10 year old brother gets to go anywhere he wants, and I can’t. So sometimes it makes me jealous. Jealous is mad because I can’t do it and he can.”

And, finally, one child acknowledged that sometimes people outside the caregiving relationship make decisions about the child that they lack the information and understanding to make. An example would be deciding that because of the ventilator the child could not play a particular game. Emphatically, he rebuked:

“Don’t leave them behind just because you decide they can’t do it!”

Normal/Different.

Normal/Different described experiences the child had with other people.

“Normal” implied and described a benign response to the child. In the “Normal” aspect of this theme, the child experienced no particular emotional surprise, reaction or response by the other person. “Different” was expressed as response from the other person that suggested to the child that he/she was dissimilar, unlike others, and this response was often interpreted as insensitive or thoughtless. One child sought to explain why non-care-giving others had such difficulty with someone who had the need for a ventilator.

Insightfully she allowed that often others did not have the same experience and to them she *was* different. She said:

“It’s pretty normal for you and your family...but people from the outside. they don’t really know how it works and you have to explain it to them...”

But another child instructed that it should not matter that there was something out of the understanding of others. There should be acceptance:

“Just like you are outside and see somebody, don’t wonder what they have or why they have it or anything. Just know they are regular people and they need a little help breathing.”

Yet another reminded that there really is not anything unusual going on as she said:

“There is nothing wrong with me. I’m normal, it’s just I have a tube in my throat and a ventilator and I’m in a wheelchair that moves!”

This participant also went on to describe what normal meant:

“Normal is me...what I do normal is what other kids do normal. I watch TV like normal kids, I eat like normal. I just eat like everybody, fork, spoon, knife whatever. I do not have a feeding tube. I go outside to play. I can’t run or walk, but I am still able to play. I have races with all the kids. They are on their bikes and I am in my wheelchair and I race them. I just make myself normal, I guess...I have practically a normal life.”

Since telling others about their devices seemed to be the mechanism for assuring their being considered normal, some participants went on to suggest specific instructions:

“I tell them what happened and why I have a trach up in me and why I have to have one. And, if they want, I show them.”

Another participant said:

“Most of the time they ask me silly questions...They just look at you with this weird face like ‘you’re nuts!’”

Being different, however, meant that the participants sometimes felt that other people were thoughtless to them as human-beings. Most participants were quick to note that they had experienced insensitive remarks and behaviors. One participant spoke of how other children reacted and noted that she excused the smallest of them because they were too young to understand. She was willing to show her machine, and tracheostomy and told the interviewer how medications were administered as they were actually being administered. Another participant remarked that she had come to understand being different even if others did not understand. She said:

“Ever since I was 10 and realized what my disease was, my mom told me I was special...ever since then I have thought of myself as special and special means that I have something most kids don’t have...I tell myself it is good because some of the kids don’t know about the real world and life and stuff and my mom says I do because I know about doctors and death and heaven and everything...everyone is different and special in their own way...I sort like being my special person.
(pause) God makes all people different and special.”

Summary

The experience of the ventilator dependent child takes place within the context of others: a human other and a mechanical-other. For this reason, the children report never being alone. Within this context, the experience of the ventilator-dependent child was described by these overarching themes: I'm still a person!, Can/Can't and Normal/Different. As described by participants, the children reported they are aware of who they are, the limits to their ability, and how others respond to them. All participants were articulate in reporting how they should be acknowledged and cared for; in addition they all demonstrated expert knowledge of their mechanical and personal needs. Moreover, they articulated a willingness to be flexible and adapt according to the necessity to do so in order to accomplish a particular objective.

The overarching theme as described by these children was that of: I'm still a person!. Participants reported that being a child who is ventilator dependent means there are some things that Can and conversely Cannot be accomplished. Yet the participants give clear indication of their willingness to attempt whatever task is set before them. They additionally present a willingness to adapt their manner of accomplishment as need to do so arises. Finally the participants described their abilities as sometimes Normal and sometimes Different balancing that against non-disabled persons in their environment. Yet they accomplish much in both aspects of the theme. Each of these themes have been revealed in the words of the participants as found in the transcribed interviews.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to describe the first-person experience of children who are ventilator dependent. Interviews were completed with nine children using the phenomenological approach described by Pollio, Henley and Thompson (1997) and Thomas and Pollio (2002). Verbatim transcripts of the interview recordings were interpreted both by the researcher and in phenomenological research group meetings. The analysis of these transcripts revealed a thematic structure for the experience of being the child who is ventilator dependent. These themes all emerged against a ground of Other and Never Being Alone. From this ground the figural experience was described in terms of: I'm still a person!, Can/Can't and Normal/Different. This chapter will discuss this thematic structure and its implications for nursing practice, education and research.

Thematic Structure

The experience of the child who is ventilator dependent is grounded in experience of Other and Never Being Alone. Each interview transcript was clearly oriented in terms of the Other or toward the grown-up(s) on whom the child depended. Each participant identified various persons who was experienced as the Other. For most children, the primary figure in this ground of the Other was their mother. The second most frequently identified person was a nurse, although no specific nurses were identified by name by any

child. Additional persons identified included siblings, doctors and, on one occasion, a father. Each participant identified or alluded to caregiving tasks that the Other provided to him or her. Also, evidence of spontaneous caregiving was evident during several interviews. During one interview, when the ventilator alarm sounded, the nurse caring for the child responded. In three situations, the mothers remained close during the interview, yet out of the visual fields of the child. During one interview, the mother was overheard ordering pizza for lunch. In another case, the mother appeared frequently to wipe secretions from the child's mouth as the interview went on without interruption.

Some children even commented on what would happen should the Other not be present or be unresponsive to their needs. Most often, the Other not being present was expressed as a threat to breathing or even to life. The Other was clearly a pivotal point for survival, and most often was the participant's mother.

An experience of the mechanical Other was constituted by any of those machines the participants required to replace the essential function of respiration. Participants were quick to identify, quite specifically, what type of machine or machines they used. All had sophisticated understanding, albeit simple explanations, for the functioning of each of their machines. Moreover, all the participants knew how their machines could malfunction and described what happened when they did malfunction. All of the children knew of the electrical and battery requirements and most of them understood the principles of changing circuits, re-charging batteries and keeping the devices dry. Not unlike their understanding of the essential nature of the human other, the machine was

also an imperative without which they could not live. Of this, the participants were certain and gave evidence in their own words.

This finding substantiates once again the importance of the mother to the life of the child. Diverse works from classical developmental theory to contemporary parenting handbooks and child development/child care research often emphasize the mother as essential to the life of the child. The same is true for the child who is ventilator-dependent. This finding is consistent with other research that acknowledges the mother as the most likely person to be the primary care giver to the child with special needs (Teague et al., 1993).

Often the grown-up Other in attendance to the child is the mother of the child, but this was not always true. As noted, the other person could be a nurse, the father, a sibling or a physician, in essence a surrogate for the mother. In every case, the children implicitly trusted the Other, whether they were the child's mother or not. Also, in every instance, the child's mother organized and directed the child's care, even if she was not always the provider. Consequently, trust was transferred from the mother to the Other who had been made responsible for care delivery and was then expected and relied on to carry out his/her charge.

Relationship of Developmental Theory to the Study Findings

Findings of this study could be considered through the psychosocial developmental theory proposed by Erikson. Erikson (1950, 1964) wrote extensively of

the psychosocial development of the child, theorizing that the nurturing relationship between the mother and her infant formed the foundation for the child to become a successful, functioning, fulfilled adult. Because of the mother-child relationship, the child developed the ability to trust, develop autonomy, develop initiative, become industrious and develop his or her own unique identity.

In the first psychosocial developmental stage, the child manifested nurturing needs that were recognized and met by the primary caregiver who, usually, was the mother. If those needs were met appropriately, the child achieved a sense of trust and moved on to the next developmental phase (Erikson, 1950,1964). Although the mother of the child orchestrated the care for all the research participants, there is evidence in the children's narratives of the accomplishment of this first developmental stage and the trust that they have in their human Others to provide for them. Nurturing relationships between the Other and the child must be ongoing for the child to survive.

Erikson (1950,1964) further theorized that the child must achieve autonomy to prevent the development of shame and doubt in the second stage of child development. In the process of accomplishing autonomy, the child must use the mother as a touchstone for security. That is, the child, figuratively, moves a bit farther from the mother returning frequently to mother to re-charge the autonomy potential. This is where an interesting shift occurs in the progressive development of the child who is ventilator-dependent and who cannot become entirely autonomous, from a physical perspective, from the Other.

The period of autonomy versus shame and doubt, from approximately one to three years, recognizes the child becoming independent in their personal feeding, toileting, mobility and language communication skills. This theoretical proposition does not suggest that the child has no further need of a caregiver, yet that the need for the other in the child's existence is different. For the child who is ventilator-dependent from infancy, this shifting to a state of greater independence may or may not occur in the currently accepted developmental time-frame. The child who loses these self-care abilities when becoming ventilator-dependent at an older age relinquishes the self-care abilities accomplished in early childhood back to the mother who either provides or orchestrates the care needed by the child. Yet it was fascinating that regardless of the circumstances causing ventilator dependence, there did not appear to be any indication that, developmentally, all was not as expected. Neither was there any acrimony apparent as the children depended on the Other to provide for their physical needs. Indeed, in all cases, the children, who clearly trusted their grown-up Others, did as much as their functional ability gave them the opportunity to do. Regarding this, direction can be taken from the child who revealed that, "You just don't worry about what you can't do, you just do what you can do and worry about the stuff you can't do later and think of some way to do the thing that you can't do now, so you may be able to do it later." As such, in addition to achieving the developmental tasks of trust and autonomy, children who are ventilator dependent also accomplish the psychosocial task of initiative in spite of the various challenges they face and different abilities they possess.

School as described by the children was where they “learned a lot” about various things. School provided an opportunity for cognitive achievement whether it occurred in the home or in the public domain. There were things the children individually liked and disliked. Also, it was obvious to them that there were activities at which they excelled in contrast to things where they had to really study to learn. This finding is not unlike what would be expected in the experience of any school-age child. Further, in this period of what some describe as “energetic learning,” playing and working fully allow the child to develop “a real sense of accomplishment and satisfaction in their activities” (Wong, 1999, p. 701) In addition to learning, the children indicated they had the opportunity for social encounters at school. School friends came and visited in the children’s homes and were visited reciprocally. They connected and communicated by telephone and electronic mail. There was outside play, riding around the track, playing ball, playing chase and playing with pets to name but a few of the activities identified in the children’s narratives. Thus, the school, play and social experiences of the participants were quite similar to those recognized in other children. Again one notes, as Erikson (1950, 1964) suggested, the experiences of the children had promoted the development of the sound self-concept they all revealed and the children demonstrated their achievement of industry as they moved on in the formation of identity.

The experience of the ventilator-dependent child was additionally situated within a contextualized ground of Never Being Alone. This aspect of the ground was intensely interwoven with the ground of the Other to the extent that the two described aspects are

inseparable. The children all indicated in their narratives that they could not be left alone: they must be accompanied in all their activities of daily living, recreation, school and most especially (as noted) when they sleep. The participants were aware of the vigilance of the Grown-up Other, and the mechanical Other, as necessary components of lives. And, although one child perceived this as being intrusive, for the others there was an expectation that someone would always be there.

Themes

I'm still a person! This theme was dominant in both its presence and its occurrence in all of the interviews. All the participants were emphatic that they were people of worth to themselves and others. They were quick to verbalize what they knew about themselves and their experience and what they wanted to make sure other people knew. They were quite passionate about their expectations of respect as people. It was in the revealing of this theme that there appeared an apparent gender-related difference in the responses of the participants during the interviews. The female participants were willing to discuss, at length, many and various aspects of their experiences. The male participants, however, were more reticent to continue in the conversations after they made their particular point. In one case, the participant constantly chewed on his mouth stick (that he used to control his motorized wheelchair) and smiled to any urging, on the part of the researcher, to comment further. In another case, the participant resorted to telling made-up jokes about anything he could think of, specifically animals with

interesting characteristics, which he obviously found quite funny and entertaining. A third changed the subject after he pronounced his particular statement only to re-focus on something entirely different and began to speak of his hobbies. It was clear that they (the male participants) had said what they considered essential about their experience. These avoidance behaviors were entirely absent in the female participants.

The theme I'm still a person! revealed much about the participants. This sense of self and their abilities were reiterated time-and-again as they described how they played with siblings, went to school, sang in choirs, and were actively participating members of their families and communities. It was clear, from the youngest to the oldest participant, they recognized themselves as valuable and contributing members of their families and communities. This finding suggesting a valuing of self is consistent with conclusions of a recent study by Noyes (2000) who interviewed adolescents who were required to remain hospitalized as a result of ventilator-dependence even though they were physiologically appropriate for discharge home. This study of 18 participants indicated that when compared with the United Nations Convention on the Rights of the Child, the rights of these young people were violated in their unnecessary confinement to the hospital setting further compounded by lengthy and poorly handled discharge procedures, loss of education time, and inability to maintain sufficient contact with belongings, family and friends.

Can/Can't. This theme was emphasized by each of the participants and presents an interesting new construct. The participants were clear and straightforward about what

they could and could not do, physically and cognitively. Furthermore, they were quite emphatic about finding alternate methods for accomplishing that which could not be accomplished in a more conventional manner. One child revealed, for example, that if she had slippery pants on, she could slide herself into bed. Another participant demonstrated how he moved around using a mouthpiece to control a mechanical wheelchair. Another noted that the new mechanical wheelchair she had received made it possible for her to come up the incline into her home more easily and independently. The same wheelchair also gave her the experience of “popping wheelies” because as she moved up the hill, the center of gravity shifted.

It was remarkable to note that despite what the children indicated they could not do, there was no rancor. There were statements and shoulder shrugs, but no bitterness, nor even evidence of sadness. Their expressions revealed simply a matter-of-fact perspective of themselves, regardless of the perceptions of other people. One child, though, who was the exception among the other participants, indicated some very different feelings about using the ventilator and expressed that when he was attached to the ventilator each night, he felt pulled away from others, even “sucked into a black hole.” This was an undeniably unpleasant experience for him. He further reflected that when he was attached to the ventilator, the experience was similar to being tied in the yard like a dog. He was, of all the participants, the only one who acknowledged both that the ventilator gave him opportunities he otherwise would not have had but also that he had a negative perspective of the same.

Normal/Different. This theme emerged from the participants' acknowledgment of how others responded to them. All the participants revealed their extraordinary skills of observation especially of those in their environment who were not necessarily members of their intimate circle of family and caregivers. Participants expressed awareness of being stared at and what that might mean to those who were staring as well as a concern about how the person staring would respond should they be confronted. One participant suggested that if small children stared, that it was because they were young and did not know better. The same participant reported that she would tell older persons who stared to "take a picture, it lasts longer" as they stared, in her opinion, inappropriately. "Normal" was how the participants felt about themselves. "Different" was how the participants believed others considered them. The dichotomy reflects how the child experiences his or her existence in contrast to how the child thinks others outside of their world think they exist. The participants indicated with their words that other persons would come to recognize them as normal if they attempted to learn about the participants' experiences and abilities. Additionally, the participants believed they could teach others the information they needed to understand the experience of the ventilator dependent child if they were given the opportunity to do so.

The determination to achieve and influence the knowledge and understanding of others was paramount in all participants. Of interest, a similar concept of normalization was described recently in a study by Wilson, Morse and Penrod (2000). In this study of 17 ventilator-dependent children at a 6-day summer camp, data gathered from the

children and their primary caregivers (16 mothers and 1 father) allowed the researchers to frame a description of normalization as a process whereby life is lived as it would be by non-disabled individuals in order for the child to integrate into society successfully. In making others in their communities aware of their existence, understanding, and abilities, the participants in the present study contributed to a process of normalization for themselves.

Hearing the Voices of the Children

The most significant outcome of the present study is that indeed the children's voices have been heard. In this, the first research detailing first-hand interviews of children who are ventilator-dependent yet not only exist, but grow and develop, play and go to school in the face of tremendous adversity, there is much to be considered and learned. Yet, these children exist in the world in a different way. The following section will consider how these participants have managed to respond to their experiences in such a positive manner and suggest that their response is an outcome of the unmistakable resilience they possess. Implications for nursing practice, education and future research will follow.

Relationship of Resilience Theory to the Study Findings

The children who participated in this study all existed as a result of medical technology and required a mechanical device to replace a part of their bodies that did not function sufficiently to sustain their lives. Often referred to as "survivors," as indeed these children literally and figuratively are, children who experience devastating events in their lives and are then able to successfully cope are termed "resilient" or may be full of "resilience." Evidence of coping can be found in the children's ability to successfully grow and develop, as reflected in age-appropriate academic and social accomplishment. The participants in this study are indeed resilient as indicated by their connections to age appropriate activities at home, in school and in their respective communities.

Resilience as a protective and restorative attribute is of especial interest with regard to children who "in this modern, complex society are 'at risk' of failing to succeed in life because of the adversities in their young lives" (Rak & Patterson, 1996, p. 368). "Such children stand little chance of meeting their potential as adults...they are likely to become so dysfunctional that they may not be capable of self-support or rewarding relationships" (Hanson & Darta, 1995; Rak & Patterson, 1996, p. 368).

Nursing literature indicates that resilience has been most studied in various aspects of psychosocial nursing and with adolescents and adults. Research by Wagnild and Young (1990) described the successful adjustment of older women as evidenced by their involvement in a senior citizens center subsequent to spousal loss. Research of family climate and the parent-child relationships of adult children of alcoholic fathers by

Tweed and Ryff (1996) suggested that the resilience was related to the positive functioning of the members of their study group. Howard (1997) suggested the need to explore "resilience paradigms" and to develop therapeutic interventions to foster the effectiveness of substance abuse therapies with adolescents. Research seeking to discover how nurses can support healthy adaptation to implanted life-sustaining technology by Beery and Baas (1996) described the symbolism and theory of the medical therapeutic as well as resilience as a value for the recipient of the device.

Dyer and McGuinness (1996) have suggested resilience is "the ability to bounce back from adversity...[and] helps us to understand why one person reacts with symptoms to an objectively minor event when someone else may not experience distress even in the face of apparent major disruption. Resilience evokes the promise of something good resulting from misfortune, hope embedded in adversity (p. 276)." Polk's (1997) middle-range nursing theory suggests that resilience is "The ability to transform disaster into a growth experience and move forward" (p. 1). Stewart, Reid and Mangham (1997) identified and discussed the proliferation of resilience research in recent years and consider resilience especially relevant to the nursing of children.

The most important consequence of resilience may be the reduction in occurrence of various functional comorbidities. If humans are resilient, then they are able to function at the optimum level positively responding to a wide range of challenges. "Resilience is concerned with individual variations in the response to risk" (Rutter, 1987, p. 316). Additionally, Garmezy (1991) wrote that resilience is "the capacity for recovery and

maintained adaptive behavior that may follow initial retreat or incapacity..." (p. 459).

Thus, resilience is a complex, multi-faceted attribute of children who have experienced what may be objectively viewed as an overwhelming event or combination of events but have successfully moderated the negative impact. This type of response takes into consideration the whole range of the potential developmental aspects of the child (Wong, 1999). The resilient child will be able to experience optimal growth and development allowing them to escape the potentially negative effects of, as in this case, chronic illness and technology-dependence.

Researchers have attempted to identify specific components of resilience that would allow for strengthening through therapeutic intervention, the purposes being to foster the resources or protective factors of the child, reduce the emergence of morbidity, and promote development. Components of resilience may include likeability and sense of humor on the part of children who identified as resilient by teachers or parents.

Specific antecedents include: (1) intelligence that gives evidence of learning potential academically (and problem solving) and socially; and (2) the ability to connect to people in the immediate family and in the greater community accomplishment (Brooks, 1994; Dyer & McGuinness, 1996; Floyd, 1996; Garnezy, 1991; Giordano, 1997; Poulsen, 1993).

The participants in this study are exemplars of children who are resilient as either a part of or an outcome of the adversity they experience. Regardless of the cause, ventilator-dependence demands life-long adherence to costly, time-consuming and often

uncomfortable (or even painful) therapeutic intervention. Ventilator-dependence results in challenges to all aspects of human function. Yet, the participants in this study described their experience with equanimity, clarity, and understanding. They understood much about themselves, their machines and their needs. They connected to others outside of their immediate families. They went to school, learning with and playing with others. They had fun. As resilient children, they were able to function at their optimum level positively responding to a wide range of challenges creatively problem solving as the need became apparent. The future may be uncertain for the participants of this study and many people will not understand their experience. Yet, clearly they coped effectively and demonstrated social and academic accomplishment appropriate for age exemplifying the current understanding of resilience. Further research is necessary to broaden the understanding of resilience and expand study of children who succeed in spite of significant health-related adversity.

Implications for Nursing

Implications for Nursing Practice

Children who are ventilator dependent are now routinely cared for at home within the structure of the family. Home care of this nature has become a treatment of choice and with the continuing drive to keep medical expenditures as conservative as possible, it is unreasonable to expect the need for this type of home care delivery to decrease anytime in the future. Yet as accustomed to home care for children who are ventilator-dependent

as nurses have become, it is still an remarkable experience for the child and his or her family.

Nursing practice often focuses most intensely on the physical aspects of the individual's circumstances that require various psychomotor skills as the nurse assists the patient to maintain and respond to challenges to their health. Nursing, however, more than a simple response to physiologic demands, is also a holistic approach to responding to the call of the person for care they cannot provide to themselves. Nurses provide care to individuals, families, groups and communities. Chronic-critically ill children, dependent on life-sustaining technology for their existence such as those who are ventilator-dependent, demand carefully coordinated, complex care management by nurses cognizant of the impact of the entire experience on the child, the family and the community.

In the case of children who are ventilator dependent, the results of this study emphasize the need for the nurse to collaborate with the care recipient, both the child and the grown-up Other, as together they plan care that supports the child as he or she achieves the highest level of function possible. The nurse must use excellent communication skills to holistically assess, understand and interpret the situation of the child. Assessment must include a focus on the strengths the child brings to their situation and how the nurse can support and enhance their way of life. This is of incomparable importance in these circumstances. The child is a well individual, with exceptional needs that includes mechanical support and constant human attention.

Of great importance for the nursing practice that includes care for these special individuals is to fully comprehend that the child is not a passive care recipient. Research participants were comprehensive in their understanding of their circumstances and their needs. They could articulate the same in a clear and understandable manner. It is essential that nurses listen to their words and hear what they are saying, in contrast to assuming that they know what the child needs better than the he or she does. This approach demands that nurses be authentic in the care of the child, utterly present, as he/she delivers care, trusting as well as trusted.

Considering children who are ventilator-dependent as resilient or having resilience guides not only the understanding of these remarkable young people and their successes but also the therapeutic interventions nursing can deliver to further extend the concept of successful social integration and normalization while protecting them from psychosocial comorbidities. Children must be assisted to develop the components of resilience in their lives. Finding someone outside their immediate families with whom to connect is essential, as has been demonstrated by the participants of the present study. Moreover, nurses must assist children to achieve their cognitive potentials, while allowing and encouraging them to continue assuming responsibility for understanding their own individual needs. Finally, to assist the child's adjustment to their adversity, nurses must assist them as they adapt routines and activities striving with the child to make all things as possible as they can be.

The role of the nurse for the child who is ventilator-dependent, in addition to being an excellent care provider in this specialized area of practice, is in the realm of primary prevention and health promotion, and sometimes in restoration. Subsumed under the responsibilities for health promotion must be community education and child advocacy. Children who are ventilator-dependent recognize that others in their communities identify them as “Different” and that this identification sometimes leads those people to be insensitive to them. This community need informs nursing practice in the role of community educator regarding children who are disabled, demanding advocacy not only for them as individual human-beings but also for their potential. The nurse should actively engage in conversation at both local and national levels demanding excellent care, complete access to care and recognition of these valuable and contributing young people. Often, it is remarked that children are our future; these children are part of our future, too.

Implications for Nursing Education

Nursing education gives opportunity for dissemination of the essential knowledge that prepares an individual for the professional practice of nursing. Graduate or masters preparation prepares experts in a clinical areas and doctoral preparation produces researchers to continue building the science.

Nursing of persons who demand chronic mechanical ventilation in the home is certainly a specialized area of practice within the home care arena. In addition to timely recognition of the physiologic demands of their patient, the nurse must recognize the

special needs of a child growing up in this situation and their impact on the family and community.

Generalist preparation, occurring at the undergraduate level of nursing education, must include an emphasis on developing interpersonal skills that call attention to comprehensive listening to the patient and his/her story. Developing comprehensive listening skills may indeed be the most important aspect of nursing education. Thus, the nurse continually collects information from which conclusions are drawn and validated with the patient. Teaching phenomenological interviewing techniques supplemented by interview practice, group discussion of findings and fostering understanding of the experiences of people would help the novice nurse develop effective and efficient listening and analysis skills. For example, "Tell me about your pain" would yield far more information than, "What is the level of your pain on a 1-10 scale?" which has become a nearly rote question. Responses to such questions in a group discussion would enhance the learning of all those involved.

Nursing educators are the first professional role models most nursing students encounter. Therefore, as nursing educators champion holistic interactions with clients, they must model these interactions with students and colleagues alike. The results of this study indicate a need for nursing educators who recognize the value and worth of the individual, regardless of their circumstance, and communicate this to their students. Indeed, it was suggested by one participant that not knowing something was only acceptable in the very young child. Thus, nursing educators must be open to learning

about the experiences of others. Phenomenological techniques promote the acquisition of knowledge about the unique experience and a means of acquiring real understanding of the experience.

Further, graduate education must take on the responsibility of returning some curricula to a focus on the patient, in this case the child. For a number of years, there has been an impetus to prepare nurses to function in advanced practice roles that serve to extend medical practice, as they diagnose and treat persons with the more common health care concerns. Certainly, there will be a continued need for nurse practitioner and midwife preparation that places an emphasis on the holistic care of the client. However, it is essential that we return encourage some advanced practitioners to have primary focus on the nursing care of the client; the primary focus should not be on medical diagnosis and treatment.

Implications for Nursing Research

Given the paucity of research that focuses on children who are ventilator-dependent, many opportunities for continued research exist. Had there been additional time and fiscal resources, this study would have been greatly expanded to include more children, from a broader geographic representation. From a demographic perspective, there is a distinctive evidence of the need for a thorough identification of the true population of children (including infants and youths) who are ventilator-dependent. This would be a costly and time-consuming endeavor. In light of the recent national tragedy, there is an even greater need to collect demographic information, identify resources for

support of children and their machines, and maintain records of medical and contact information. Certainly recent national data reveal the true number of children with chronic illness and their relative degree of impairment (Newacheck, 1998), but the numbers and types of devices on which they are dependent has either not been assessed or has not yet become available. There is, additionally, no resource where one can determine the availability of services and resources for these children and their families across the nation, let alone around the world. Given the mobile nature of society in the United States, this unnecessarily restricts the movement of a child and their family from one location to another. Further, this lack of resource material contributes to limited opportunity for these young people as they become adults and transition to independent living in the community.

Other opportunities for continued research focus on gaining continuing understanding of the experience of ventilator-dependent children as they grow into adulthood. Here phenomenological interviews with the participants in this study throughout their lives, as well as others with special needs, might provide additional dimensions to help in understanding their experiences.

Further understanding of resilience is essential as is the development of theoretically derived mechanisms for fostering resilience. This understanding of the process and product of resilience would promote development of nursing interventions designed to be utilized with all children who experience life-threatening health care challenges and other types of adversity. Additional research would be especially useful

for parents and siblings of these special people to gain a comprehensive understanding of the world of ventilator-dependent children and how they best grow and develop within a family-centered environment. Simultaneous interviews with families as well as focus group interviews with multiple children or adolescents who are ventilator-dependent would give a broad entrance into a world that can only be clearly understood by the persons who exist in the experience. Further, such understandings would improve the negative acute care experiences that chronic-critically ill persons invariably have at times, supporting a better understanding of the needs and desires of the children and families and fostering efficacious discharge planning and re-integration into the home and community. Since long-term mechanical ventilation at home has become the accepted therapeutic management for ventilator-dependent children, this research is needed in order to provide appropriate nursing care to all those persons involved in the ventilator-dependent experience. The present study, that describes the experience of the child who is ventilator-dependent, provides the beginning for such work.

Finally, this research contributes to the current evolution of the phenomenological methodology described by Pollio, Henley and Thompson, (1997) and Thomas and Pollio, (2002). Research using this specific procedural methodology had not previously been done with children, let alone children who are ventilator-dependent. As such, the project revealed the usefulness of the methodology as well as a number of things about research with children, especially those with unique physiological requirements.

It is now obvious that children are indeed capable of providing vivid accounts of the experiences of their lives and are willing to share them with relative strangers who give evidence that they are interested in what the children have to say. Indeed, each research participant in this study, with poise and composure, revealed his or her unique experience. The language they used was clear and unburdened with extraneous matters. They could and did respond to the questions asked of them. They did not become fatigued or bored. As was commented on in Chapter 1, the children did willingly tell the story of their worlds. The understanding they shared as participants of this study was apparent. This particular group of research participants and the findings of the study inform the process of phenomenological interviewing with school age children. It is evident that research with this age group can and should include other topics of importance to nursing science. Further research will demonstrate the ongoing commitment to a more precise understanding of the experiences of children and give further evidence to the value of children in society.

Concluding Remarks

The journey taken from the inception to the completion of any project is long and arduous. This is not less true for this study. There are several concluding comments that bear consideration.

First, the experience of being ventilator-dependent as described by the children who participated in this study is at the very least difficult. The transcripts evidenced little

of the daily physiologic challenges faced by the children and the intense physical and psychological effort generated by their mothers to care for them in homes that included numerous devices, other children, pets and outside persons charged with delivering care to their special children in their absence. The mothers' story is yet to be told.

Second, in discussing the results of this study, the findings were considered through the lens of traditional developmental theory as proposed by Erikson. It is imperative to remember that this was a conventional way of giving order to discussion of the findings. The children who participated in this study did grow and develop as one expects all children to do. Yet, their development cannot sufficiently explained through traditional theory. Researchers must stretch and expand developmental theory to accommodate these truly special children and their on-going process of growing-up. Indeed, these resilient and special children are in the world in a different way.

Finally, it is imperative, in the broadest sense, to remember that these children do live as an outcome of extraordinary technological development in health care. They are healthy beings, often as well as they can be. They are part of the growing population of those persons who might be known as chronic, critically ill. Their physical and health care needs challenge our thinking. The continuing cost of care for them will challenge fiscal resources. They must remain visible. Their stories must continue to be heard.

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APPENDICES

APPENDIX A: Institutional Review Board Approval

THE UNIVERSITY OF TENNESSEE



Institutional Review Board
Office of Research
404 Andy Holt Tower
Knoxville, Tennessee 37996-0140
865-974-3466
Fax: 865-974-2805

February 16, 2001

IRB #: 5974 B

Title: Living with a Machine: The Experience of the Child who is Ventilator-Dependent

Sharon Isenhour Sarvey
Nursing
318 Northway Dr.
Berea, KY 40403

Dr. Sandra Thomas
Nursing
1200 Volunteer Blvd.
Campus

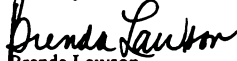
At the meeting of the Institutional Review Board (IRB) held February 15th, the above protocol was reviewed. The following is the result of that review:

The motion passed to approve pending receipt of the following revisions to be submitted to the Compliance Office.

- State the location(s) (Kentucky, Tennessee, etc) where the study will take place.
- The assent form should be revised to indicate that the transcribed data will be shared with a research group whose members will sign a confidentiality statement.
- Explain the storage of the audio tapes for five years.
- State exactly when the audio tapes will be destroyed.
- Include a statement in the parental information sheet that there is no penalty for withdrawal from the study.
- Add a sentence that indicates no risk or change in receipt of current health care.

The Committee has placed a limit of sixty days from the date of this letter for placing the protocol in acceptable condition. Therefore we must have your response on or before **April 16, 2001**. Please do not hesitate to call me if you have any question.

Sincerely,


Brenda Lawson
Compliances

APPROVED
By IRB - Brenda Lawson
Date 2-19-01

APPENDIX B: Parental Information and Consent

Living with a Machine: The Experience of the Child Living with a Ventilator

Your child is being invited participate in a research project to learn more about the experience of children who live some or all of the time with mechanical ventilators.

I want to know more about children living with ventilators. This project is being used to increase what is already known about children who live with ventilators. I hope that this information will be useful to assist in medical care, school planning and program and legislation for all children with special health care needs especially those who require machines to live. Additionally, this project will provide much needed information to nurses about a very special group of young people.

Participants in this study will be children who are dependent part or all of the time on a ventilator. They also will be asked for their permission to be a part of this project and to be tape-recorded during a conversation with me where they will be asked to share with me the experience of their ventilator. Children will also be asked to give some information about themselves, their school, brothers and sisters, hobbies, pets, chores, etc.

I will talk to your child at a place and time that is convenient to you. Your child will be interviewed alone only after they tell me that it is all right to go ahead. The conversation will be tape-recorded. Nothing else is involved in this study. I do not expect to have more than two conversations with your child and probably one will be enough. The first conversation will last 30-60 minutes. Only some of the children will be asked to participate a second time. During the second conversation, some of the children will be asked whether or not I have understood what they have said during the interviews. There will not be any further tape-recording after the first interview. **** If at any time during our conversation your child becomes too tired and wants to stop or decides they want to stop for any reason, we will.**

I will not share the conversations with anyone else. Tapes that are recorded will be transcribed before the information on them will be used. Recorded tapes will be kept in a locked place controlled by me for my use only. They will be destroyed after five years. What your child says will be grouped with what other children's comments so that no one child's comments can be identified. Transcripts will be kept and may be looked at again at a later point in time. No information will be given in oral or written reports that could identify you or your child.

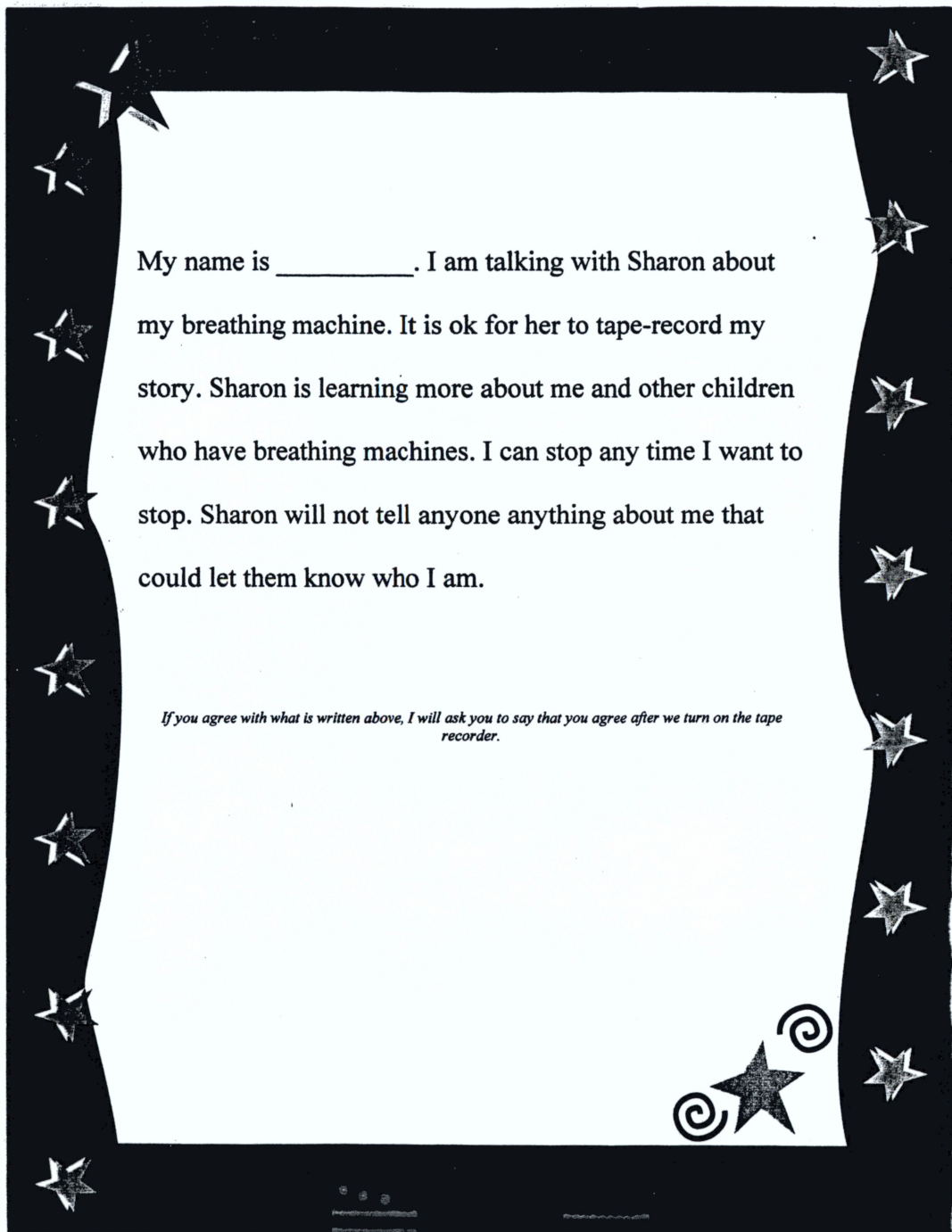
If you have questions at any time about the researcher, the project or how I will do the project you should contact the researcher, Sharon Isenhour Sarvey at University of Tennessee, College of Nursing, 1200 Volunteer Blvd. and (865) 974-4151 or at 859-986-8641. If you have questions about your rights as a participant, contact the Compliance Section of the Office of Research at (865) 974-3466.

Your child's participation in this study is voluntary. There is no risk to your child. If your child agrees to have a conversation with me he/she may stop the conversation at anytime. If your child decides to stop the conversation and does not want to continue, the tape will be destroyed. There is nothing that will change in your child's care as a result of any decision to stop the conversation. If your child becomes ill during the interview, we will stop and reschedule. If your child is sick on the day of our appointment, we will reschedule our time.

If you understand the above and agree to your child participating in this study, I will ask you to read the following statement into the tape recorder as we begin.

*I have received information about this project and have had the opportunity to ask questions. I have read the above information and agree to my child being a part of this project.
I have received a copy of this form.*

APPENDIX C: Child Assent



My name is _____. I am talking with Sharon about my breathing machine. It is ok for her to tape-record my story. Sharon is learning more about me and other children who have breathing machines. I can stop any time I want to stop. Sharon will not tell anyone anything about me that could let them know who I am.

If you agree with what is written above, I will ask you to say that you agree after we turn on the tape recorder.

APPENDIX D: Confidentiality Agreement for Research Group

Confidentiality Agreement

As a member of the Qualitative Research Group in the College of Nursing under the direction of Drs. Howard Pollio and Sandra Thomas at the University of Tennessee, Knoxville, I agree to guarantee confidentiality to subjects who participated in the study entitled "Living with a Machine: The Experience of the Child who is Ventilator-Dependent." I will not publicly reveal information I have learned.

Signature

Date

VITA

Sharon Leigh Isenhour Sarvey was born in Pensacola, Florida to a young Navy pilot and his wife. She attended numerous schools in the United States and graduated from Booker T. Washington High School in Norfolk, Virginia in 1975. In the fall of 1975, she matriculated to the University of North Carolina at Chapel Hill. She completed the baccalaureate degree in nursing at East Carolina University in Greenville, North Carolina December 1980 and the Master of Science in nursing from that same institution in December 1988.

Sharon's nursing career has included nursing in the community-based hospitals and major medical centers. She has been an educator at various levels teaching chiefly in liberal arts-based baccalaureate programs. Sharon taught for six years at Barton College in Wilson, North Carolina and currently is an assistant professor of nursing at Berea College in Berea, Kentucky.

In January 1997, Sharon enrolled in the doctoral program in the College of Nursing, University of Tennessee, Knoxville as a part-time student. She completed the Doctor of Philosophy degree in November 2001.