

THE EXPERIENCES OF MOTHERS CARING FOR
VENTILATOR-DEPENDENT CHILDREN:
A PHENOMENOLOGICAL STUDY

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DENISE M. ENGLISH



The Experiences of Mothers Caring for Ventilator-Dependent Children: A
Phenomenological Study

by

Denise M. English

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ABSTRACT

There is an increase in the number of families caring for ventilator-dependent children at home. The experience of primary caregivers, usually mothers, providing care with complex technology is multifaceted. This study attempted to provide insight into the experiences of mothers caring for ventilator-dependent children using a phenomenological perspective. The participants included five mothers caring for their ventilator-dependent children. The data were collected by way of unstructured interviews. Through the use of van Manen's (1990) methodology, the thematic analysis identified five themes: (a) taking charge, (b) "full-time nurse, part-time mom", (c) loss of personal freedom, (d) forgotten mothers of forgotten children, and (e) thinking about the future.

Findings of this qualitative study have implications for nursing practice, research, and education. They have particular relevance for policies regarding the provision of additional supports for mothers caring for their ventilator-dependent children at home. The findings will increase the knowledge base of nurses who have the potential to be key resources in the coordination of services once the child is discharged from hospital.

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Dedication

This thesis is dedicated to the mothers who willingly took the time from their demanding schedules to participate in this study. I appreciate the privilege of sharing your experiences.

CHAPTER 1

INTRODUCTION

This phenomenological study examines the experiences of mothers who provide care to their ventilator-dependent children at home. Ventilator-dependent children comprise a subgroup of a larger population, who are also identified as either medically fragile, medically complex, technology-dependent, or Children with Special Health Care Needs (CSHCN) (Capen & Dedlow, 1998; Leonard, Brust, & Nelson, 1993). The Office of Technology Assessment (OTA) (1987) defines a technology-dependent child as one who requires both a medical device to compensate for the loss of a vital body function and constant care in order to prevent death or further disability.

Over the past several years advances in medical technology, particularly mechanical ventilation, have enabled a significant number of children to survive previously fatal childhood diseases and these children are being cared for at home at increasing rates (Fleming et al., 1994; Kirk, 1998, 1999; Leonard et al., 1993; Noyes, Hartman, Samuels, & Southall, 1999; Ratcliffe, Harrigan, Haley, Tse, & Olsen, 2002). Ventilator-dependent children are not acutely ill; in fact, mechanical ventilation is a treatment for medically stable clients and not a diagnosis (Noyes et al.). Central to any discussion about children is the effect on their families, especially their caregivers. Parents and families who care for technology-dependent children at home experience significant challenges on a daily basis (Leonard et al.). My personal experience in caring for these children, specifically ventilator-dependent children, in an acute care setting indicated that it was the mother who usually provided the care to her ventilator-dependent

child at home. From the process of interviewing the mothers and encouraging them to reflect on their experiences of caring for their ventilator-dependent children, I gained a deeper understanding of their lived experience of being mothers to these children.

Background to the Study

The evolutions in medical technology have led to an increase in the use of sophisticated technology such as mechanical ventilation for children being discharged to home environments. As a result, families have assumed the responsibility for doing many of the highly skilled tasks that were traditionally performed in institutional settings (Fleming et al., 1994; Leonard et al., 1993; Patterson, Jernell, Leonard, & Titus, 1994). Factors that have contributed to the increased use of technology at home include the improvement in the survival rate of children with serious pediatric illnesses, an increase in hospital costs to provide care to these children, a reduction in payments for inpatient care that include both public and private payers, concerns about the impact of hospitalization on technology-dependent children's growth and development, and the increase in parents' desire to take responsibility for their children's care (Leonard et al., Patterson et al.).

The number of children dependent on mechanical ventilation across Canada is unknown (Canadian Institute of Child Health, 2000). However, it is known that within the province of Newfoundland and Labrador there are seven children living at home who are dependent on mechanical ventilation with an estimated cost of over one million dollars per year (D. Reddy, personal communication, May 10th, 2003).

Other national jurisdictions have kept a more careful account of ventilator-dependent children. For instance, in the United States, the Office of Technology Assessment (OTA), (1987) released a memorandum, *Technology-Dependent Children: Hospital vs. Home Care*, which documented knowledge about children dependent on ventilators, as well as those children requiring intravenous therapy, chemotherapy, or nutritional support. Although no complete data set on ventilator assisted children was gathered, the OTA estimated that there are approximately 680-2000 children under the age of 22 years requiring mechanical ventilation at home each year. As technology continues to improve at an enormous pace, it is likely that the number of children requiring mechanical ventilation at home will increase and that their care requirements will remain complex (OTA).

In the United Kingdom, a Paediatric Long-Term Assisted Ventilation group has been formed to create a database of children requiring mechanical ventilation. Although the rigour of the methodology for collecting information for the database is undetermined, it does show that the number of children requiring mechanical ventilation at home has risen from 24 cases in 1988 to 141 cases in 1998 (Noyes et al., 1999). These findings therefore, support Robinson's (1990) prediction that the number of children needing mechanical ventilation to sustain life would increase.

While many researchers have determined that caring for a technology-dependent child at home creates stress, is expensive, and involves a strong commitment from caregivers (Baginski, 1994; Hill & Thompson, 1994; Kirk, 1998; Wilson, Morse, & Penrod, 1998), other researchers noted that increased financial strain, extra caregiving

needs, uncertainty about the future, social isolation, and fatigue are additional factors associated with caring for technology-dependent children (Hazlett, 1989; Leonard et al., 1993; Patterson, Leonard, & Titus, 1992).

Whereas it is expected that family members share the responsibility of caring for their ventilator-dependent children at home, culturally, it is the mother who, in addition to her other roles, accepts the primary caregiver role (Valkenier, Hayes, & McElheran, 2002; Wilson et al., 1998), and their needs in the context of the impact on mothers have not been well documented. Only one study was located that investigated mother's experiences with caring for ventilator-dependent children at home (Wilson et al.). To date, much of the research has focused on the safety issues and cost-effectiveness in relation to home care, and the effect that the transition from hospital to home has on families (Hazlett, 1989; Leonard, Brust, & Sielaff, 1991; O'Brien, 2001; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990; Youngblut, Brennan, & Sewgart, 1994). In these studies, various family caregivers were participants. Therefore, as noted by Wilson et al., the experiences of mothers providing care to their ventilator-dependent child were captured in the larger scheme of the family system. Researchers who have focused on families caring for technology-dependent children (Patterson et al., 1992; Leonard et al., 1993; Teague et al., 1993; Youngblut et al.) found that mothers were shown to be at risk for illness, especially when inadequate respite and financial resources were available, or if they had work commitments outside the home. These researchers suggested the need for further studies regarding the complexity of mother-caregiver needs. In addition, other researchers noted that mothers are not comfortable leaving their

child with family members or friends due to the complex nature of their care (Diehl, Moffitt, & Wade, 1991; Kirk, 1998).

Purpose

The purpose of this study is to explore and analyze the experiences of mothers caring for their ventilator-dependent children at home in order to learn what it is like to live this experience on a daily basis. In addition, the findings of this study could sensitize caregivers and policy makers to the real issues of these mothers and may provide direction for practice and research.

Rationale for the Study and Problem Statement

The impetus for this phenomenological study stems from my 17 years of pediatric experience in a critical care setting, in which ventilator-dependent children are cared for. As previously noted, I found that mothers were the primary caregivers for their ventilator-dependent child; mothers affect, and are affected by, the experience in a unique way. I felt certain that these mothers had valuable stories to share with other mothers in similar situations and with the nursing community who work with them. Given my own professional interest and my awareness that little research has been done in this area, I decided to conduct a study into the life experiences of these mothers.

Gaining entry into the lived experience of a mother caring for a ventilator-dependent child can be a complex and challenging task. Phenomenology is one mode of inquiry that allows the exploration of this meaning through in-depth, thematic analysis of

narrative descriptions gathered from mothers who are experiencing the phenomenon. The research that forms the core of this thesis is a phenomenological investigation of the life experiences of five mothers who care for their ventilator-dependent children at home in the province of Newfoundland and Labrador. As more mothers undertake and share the primary caregiving role for these children, a greater understanding of their experience is essential.

Although a multidisciplinary approach is important to address the needs of children requiring mechanical ventilation, the nurse's role is critical because nurses are directly involved in preparing the child for discharge. The mothers of these children are increasingly in quest of services to support them when their children return home (Fleming et al., 1994). Using a holistic and family-centered approach and the concept of family-centered care, the nurse is the ideal person to assist these mothers as they make the transition from the hospital to home. In addition, the nurse can be extremely resourceful for care coordination once the child is discharged. Since it is mothers who assume the primary caregiver role, a greater understanding of the impact on the mother caring for their ventilator-dependent child is needed. Therefore, the findings from this study will provide a deeper insight into the mothers' experiences of caring for ventilator-dependent children at home. The information gained may benefit other mothers, as well as the nurses and other health care professionals who assist them. This study will lay the groundwork for future studies of nursing interventions to support mothers in coping with, and managing, a child who is ventilator-dependent, and it will add new knowledge in relation to the maternal experience. The focus on mothers is not to negate the important

role that fathers have in the care of these children, rather it is meant to understand the perspective of a specific group, that of mothers.

Research Question

The research question to be addressed in this study was: What does it mean to be the mother of a ventilator-dependent child?

CHAPTER 2

LITERATURE REVIEW

Because children dependent on mechanical-ventilation have chronic conditions, the sophistication of the care and the high technological skills required from family members, specifically mothers, to care for these children on a daily basis make them a unique group to study. Yet, the complexity of these children's needs sets their condition apart from the broader categories of chronic illness that include asthma, diabetes, and cancer, for example. Therefore, it is beyond the scope of this chapter to review the broader literature pertinent to chronic illness. Studies that have examined the experiences of mothers caring for ventilator-dependent children at home were the initial focus of this chapter. However, as only one research article was retrieved that explored the experiences of caring for a ventilator-dependent child from the mothers' perspective, literature pertaining to families caring for technology-dependent children, which include ventilator-dependent children, was reviewed to provide insight into family experiences. Although the research published to date indicates that technology-dependent children do well, or even better at home than in a hospital environment, it also highlights that there is a considerable effect on families providing this care, making the family experience important to understand (See for example, Hamlett, Walker, Evans, & Weise, 1994; Hazlett, 1989; Hill & Thompson, 1994; Kirk, 1998; O'Brien, 2001; Teague et al., 1993; Wilson et al., 1998).

To conduct this review, I accessed all published nursing literature from the Cumulative Index in Nursing and Allied Health (CINAHL) and Medline databases for the

years 1985-2003. The reference path included key words such as “ventilator-dependent children,” “technology-dependent children,” and “medically-fragile children” in relation to the impact of caring on mothers and families, family stress, the cost of caring, and outcomes. The articles retrieved include both qualitative and quantitative data and each identified a purpose, research question, a description of the methodology, data collection methods, research findings, and analysis of data. For the purpose of this study, opinion literature was not included. From the 125 research articles retrieved using the three-reference paths noted above, a total of 44 articles were identified that met the criteria for the study topic. The reason for the small number of articles retrieved is that many of the same articles were dominant in each reference-path.

The Impact of Technology on Families

Children who are ventilator-dependent are part of the larger group of technology-dependent children. This literature review focuses first on the larger category of technology dependence since many of the conditions and effects are shared.

The psychological effect of caring for technology-dependent children is especially difficult on families (Patterson et al., 1992). The realization that a child is totally dependent on technology for survival can have a profound impact on the family. Relationships with friends, extended family members, and those in the wider community are often changed as a result of caring for such a child at home. Multiple modifications must be made within the home environment and in personal and family lifestyles. Caring for these children at home requires a great deal of time, energy, and creativity, and

therefore, the psychological effects of technology dependence on the family may be overwhelming at times. Family routines and daily schedules are often rearranged because of appointments, home health care visits, and vendor deliveries. An even greater disruption, however, is the amount of time and effort that it takes to complete the care and treatments that are required daily and may include suctioning, changing tubes such as a tracheostomy, a gastrostomy tube, administering medications, doing physiotherapy, administering enteral feeds, and cleaning equipment for the child (Andrews & Nielson, 1988). Restrictions on the activities of the primary caregiver, usually the mother, are very prevalent among families with children dependent on technology (Anderson & Elfert, 1989; Sims, Boland, & O'Neill, 1992). A growing body of knowledge indicates that caring for technology-dependent children at home creates stress for the family. At least six researchers have studied how stress impacts on the family socially, financially, physically, and emotionally when caring for these children at home, and can be perceived as costs of caring (Leonard et al., 1993; Patterson et al., 1992; Patterson et al. 1994; Scharer & Dixon, 1989; Wegener & Aday, 1989; Youngblut et al. 1994). This section provides a discussion of the literature that addresses this area of research.

The Psychosocial and Psychological Costs of Caring on Families

What are the psychosocial and psychological costs of caring? The impact on family health and well-being when caring for medically fragile children at home was the focus of a study by Patterson et al. (1992). The researchers used the same definition to define a medically fragile child as the definition that was used to define a ventilator-

dependent child outlined in Chapter One with the exception that the authors in this study also included children who did not need technological equipment but required skilled nursing care. Their findings indicated that families requiring significant amounts of equipment reported higher numbers of physical problems than families who needed less equipment. In addition, when there was an increase in the number of hours of home care provided by parents, there was a corresponding decrease in the numbers of hours provided by health care workers, an increase in family conflicts, a deterioration in the child's condition, and an increase in the amount of money that had to be paid out-of-pocket, which all contributed to a greater negative psychosocial impact. An interesting finding from this study was the negative impact that families experienced with receiving home care services. For example, home care provided by health aides created a greater negative impact than if health professionals such as nurses provided home care. While the findings were important, the researchers did not specify strategies that the families utilized to deal with the stress.

While it was not surprising to learn that families receiving a limited number of hours of help in managing their child experienced stress, it was interesting to discover from the study conducted by Patterson et al. (1992) that help from outside home care workers was one of the greatest stressors experienced by the families. Based on this finding Patterson et al. (1994) did a quantitative study that examined the parent-professional relationship of mothers and fathers who had a child dependent on technology living at home. The study had two specific aims: (a) to determine the aspects contributing to either a positive or negative relationship with home care providers, and (b) to ascertain

the child, family, and community factors associated with conflict in the parent-professional relationship. Parents identified four positive and four negative characteristics of professional behavior. Support towards the family was the most positive aspect of having home care professionals. However, mothers (73%) felt this support more strongly than fathers (22%). In addition, parents expressed their appreciation to the professionals who genuinely cared for their child, displayed respect toward the family, were willing to collaborate with the family by asking their preference with regard to caring for their child, and were competent and skilled in providing the care.

While competence and skill of the home care professionals were viewed as positive, they also had a negative aspect when the home care providers' competence and skill were notably absent. Inadequately trained staff was the most frequent voiced concern from both the mothers and fathers in relation to the parent-professional relationship. Lack of respect for the family by home care workers and unexpected shift cancellations also added strain in the relationship. Another negative finding included the invasion of privacy, which was viewed as more of a concern for mothers (61%) than fathers (22%).

Similarly, the same theme of parent-professional conflict in relation to issues of control, competence, and trust was also found in Scharer and Dixon's (1989) study that investigated both parents and home care professionals who provided care to ventilator-dependent children. Results from the study revealed that home care professionals were as likely to experience the same positive and negative feelings toward the parents, as did the parents toward the professionals. If those power struggles exist, then it is not surprising

that the parent-professional relationship is perceived negatively (Harigan, Ratliffe, Patrinos, & Tse, 2002).

To provide a more precise measure of the effect of caregiving on families caring for technology-dependent children, Youngblut et al. (1994) utilized the Family Strengths Scale and the Family Crisis-Oriented Personal Evaluation Scales (F-COPES) to determine the day-to-day experiences of families. In contrast to some of the studies noted above, these researchers identified formal supports such as health professionals, especially physicians and nurses, as being valued resources for concerns related to treatments and changes to care as the child developed. Informal supports consisted of relatives, spouses, other parents, friends, and neighbors for concerns related to nutrition, sleep, and discipline. Most families felt that they had adequate resources to assist them in caring for their child in the way they wanted. However, as in previously noted studies, additional support to help with financial needs was identified as a requirement.

A significant concern is the intense emotional responses expressed by parents caring for these children at home. In addition to administering a standardized distress instrument (Brief Symptom Inventory) to measure psychological distress of parents caring for technology-dependent children at home, Leonard et al. (1993) also analyzed the child's illness, family demographics, and the type of home care program that families were receiving. From the number of parents who participated in the study (59% mothers, 67% fathers), 75% of the families had at least one parent who required psychiatric intervention. Factors that contributed to the mothers' stress were working outside the home, an increase in the number of hours in which fathers provided care to the child, and

additional homemaker hours. On the other hand, fathers experienced increased stress when spouses worked outside the home, if there were other siblings to care for, if they needed to rely only on private insurance to aid in caring for their child, and if the child's level of care increased. While this study provides vital information about the emotional health of parents caring for a medically fragile child, it does not describe the types of psychological, material, and social resources utilized by the parents. Uncertainty about the future, inadequate support systems, and simply, the incessant nature of caregiving are all factors contributing to additional feelings of stress (Murphy, 1997; Noyes et al., 1999; Patterson et al., 1994; Teague et al., 1993).

When examining the stress associated with caring for a child dependent on technology, it is appropriate to ask whether or not it is always within the best interest of families to care for these children at home. From the caregivers' perspective this appears to be an open-ended question that warrants exploration. In an examination of 15 families of ventilator-dependent children, for example, Hazlett (1989) explored whether or not a specific program of home ventilator management met the medical, financial, and psychosocial needs of families. While the study identified that it was families who were being studied, it was actually mothers who participated in the interviews and answered questions on behalf of the families. Despite the fact that the benefits of home care for these ventilator-assisted children included a significant decrease in cost in comparison to prolonged hospitalization, and that home care was medically safe, the majority of mothers reported that providing home care for their child was very stressful. All mothers indicated that family activities were restricted by the child's use of the ventilator. Eight of

the 15 mothers reported physical and/or mental exhaustion. Problems with home nursing care were mentioned by more than half of the mothers and home care costs were often a huge burden on families. The researcher also indicated that home care may not be the best option for all families, and suggested increased support and follow-up care if these families are to successfully manage caring for their ventilator-dependent children at home.

Social Cost of Caring

Isolation has been reported as a significant social factor associated with caring for technology-dependent children (Aday & Wegener, 1989; Diehl et al., 1991; Klein-Berndt, 1991; Patterson et al., 1994; Teague et al., 1993). Parents (usually mothers) frequently express the difficulties of being isolated in the home. Closely related to this feeling of isolation is the amount of preparation that is required for a technology-dependent child to leave the home. Equipment such as ventilators, oxygen tanks, suction equipment, and extra batteries are just a few of the items necessary to transport such a child outside the home. Even if the child is left at home, problems such as finding a suitable and trusting care provider often proved difficult, thus compounding the feeling of isolation (Harrigan et al., 2002).

The impact of isolation on families can be both positive and negative. In a pilot study of 73 caregivers of technology-dependent children, Teague et al. (1993) determined that the impact of isolation on the family had mixed effects. On the negative side, family activities were often cancelled at the last minute because of a sudden medical

exacerbation with the technology-dependent child, or the family could not find a suitable person to care for the child. The feeling of isolation was also evident in this study by the disclosure that a suitable time to conduct the interviews was a challenge. Furthermore, when the formal interviews were completed, most of the caregivers wanted to continue to share their experiences. Perhaps this echoes the limited free moments that caregivers have away from technology and the lack of opportunity they have to discuss the impact of caring for their children. Despite the negative aspects, on the positive side, 90% of the participants in this study reported that being able to care for their child's illness enhanced self-satisfaction and strengthened the family unit because of what the family members shared.

Yet, despite some positive outcomes, researchers have found that the challenges are considerable. The consequences of social isolation were highlighted in a study by Klein-Berndt (1991). The researcher reported that the medical needs of an oxygen-dependent infant were responsible for the social isolation experienced by the family. Family and friends were fearful of caring for the technology-dependent child, leaving the primary caregivers with the sole responsibility of caring for the child. Knowledge of this fear provides support for the idea of having adequate resources in place to minimize the feelings of isolation experienced by families caring for technology-dependent children (Youngblut et al., 1994).

Using qualitative and quantitative data to conduct a comprehensive review of mothers' perspectives of an in-home nursing respite service in British Columbia, Canada, Valkenier et al. (2002), presented a construct derived from their interviews and

observational data. The construct, *learning to manage the system*, consisted of a four phase process which included: *taking in, losing control, taking charge, and managing effectively within the constraints of inflexible rules*. Although the mothers found the respite service to be very beneficial, frustrations often developed especially if there was a delay from the time that their children were discharged and when they could avail of the service. Participants were appreciative of the service as it allowed the mother's time to rest, run errands, and regain emotional strength. The findings from this study highlighted the importance of meeting the needs of mothers caring for complex technology at home, their children, and their families through the provision of in-home respite services. The awareness and provision of such a vital service as described could limit the mothers' feelings of uncertainty, aid in their coping mechanisms, and promote better relationships between mothers caring for these children and health care professionals. Furthermore, the findings from this study highlights the findings of other researchers (Kaufman & Hardy-Ribakow, 1987; Olsen & Maslin-Prothero, 2001) who also supports the idea that the transition from an acute care setting to a home environment for children requiring complex technology requires a well coordinated discharge plan to assist parents and their families in their new found roles.

Lack of privacy was also identified in the literature as a social factor encountered by families caring for technology-dependent children (Aday & Wegener, 1989; Clarke, 1995; Leonard et al., 1993; Patterson et al., 1994; Scharer & Dixon, 1989). While most families are excited about bringing their child home from hospital, they must also deal with the invasion of healthcare providers and/or respite workers in their home (Smith,

1991). Initially, the presence of home care workers provides considerable support as the family adjusts to the care that is required and conforms to a different home environment with equipment, medical supplies, and so forth. However, the presence of home care workers soon infringes on invasion of the family's private space. Privacy is affected, parenting skills may come under scrutiny, and relaxation in a desired mode of dress may not be an option as caregivers may not know the exact time care workers are going to arrive (Capen & Dedlow, 1998). In addition, conflicts may arise within the home regarding role responsibility, discipline, and schedules. Heightened stress may occur if interpersonal conflicts occur with home care workers (Allen, Simone, & Wingenbach, 1994).

Through open-ended interviews with 48 families, Leonard, Brust, and Patterson, (1991) discovered that families had mixed emotions about having health care workers and respite care workers in their home. On the one hand, parents were dependent on home health care to care for their child and they appreciated the help; on the other hand the presence of these workers in the home interfered with normal family functioning and privacy. Overall, the families were satisfied with the support from home care workers; still others struggled with the idea as to whether or not having home care workers in the home was worth the invasion of their privacy. This is similar to findings of other researchers (Aday & Wegener, 1989; Leonard et al., 1993; Scharer & Dixon, 1989) who reported that loss of privacy was an issue for all families caring for technology-dependent children, but specifically for those requiring 24-hour nursing care.

Financial strain has been reported as a consistent stress (Andrews & Neilson, 1988; Patterson et al., 1994; Teague et al., 1993) since the financial cost of caring for these children is influenced by a loss of earnings (Scharer & Dixon, 1989; Wegener & Aday, 1989). In a survey of parents caring for children who required assisted ventilation, 70% of parents were not able to pursue career choices, education, or job changes because of their child. Because medical insurance would not cover the child's preexisting condition, 50% of the parents were unable to change their place of employment (Allen et al., 1994).

The Impact of Caring for Ventilator-Dependent Children on Families

Although ventilator-dependent children experience many of the same effects as other children who are technology-dependent, some of their experiences are unique due to the increased complexity of their condition. Therefore, this section focuses specifically on the literature related to ventilator dependence. Caring for ventilator-dependent children at home has a medical and social uniqueness with potential risks and benefits, and inevitable uncertainties (Capen & Dedlow, 1998). In particular, the impact on families of caring for children requiring assisted ventilation on families is one such consideration. What are the experiences of families who care for their ventilator-dependent children at home? At least five studies were found that specifically examined family stress associated with caregiving for children who require mechanical ventilation. Much of the research has been conducted in the United States (Aday & Wegener, 1988; Quint et al., 1990; Scharer & Dixon, 1989; Wegener & Aday, 1989; Wilson et al., 1998).

In addition, studies on the views of parents caring for their children who are ventilator-dependent/technology-dependent and are being cared for at home are beginning to emerge from the United Kingdom (Kirk, 1998, 1999; Noyes et al., 1999; Robinson, 1990). At least two Canadian researchers have studied the impact of families caring for technology-dependent children (Valkenier et al., 2002; McKeever, 1996, 1999). While some differences were noted in the setting and methods of data collection, the results of caring for ventilator-dependent children from the family's perspective were similar. The similarities relate to family concerns about lack of time for themselves, limited resources such as qualified workers, financial issues, interpersonal conflicts with home care workers, and parenting issues.

One prime example of family concerns is shown in a study by Quint et al. (1990) who used a cross-sectional survey of 18 families in California to assess the impact on families of providing home care to children dependent on assisted ventilation. The families identified financial resources, equipment problems, and in-home nursing as compelling concerns. Analysis of scores from the Impact on Family Scale showed no differences in the perceived impact between primary caregivers and their spouses. However, after a two-year duration of caring for their ventilator-dependent children at home, the primary caregivers showed significantly poorer scores on items that measured family closeness and self-esteem. It is possible that over time the stability of the family's well-being may be gained at the expense of the primary caregiver's coping skills and therefore requires further examination using a larger sample.

Similar findings were noted in a national study from 1984-1987 by Aday and Wegener (1988). These researchers collected qualitative and quantitative data in order to explore home care programs for ventilator-assisted children. Semi-structured telephone interviews, supplemented with mail questionnaires, were conducted with 138 families of ventilator-assisted children. The findings from the study identified the issues that need to be addressed in policy development with regards to the delivery and financing of services to both the children dependent on assisted ventilation and the families providing the care. The findings revealed that: (a) ventilator-assisted children are a unique group with complex and varying needs; (b) while families rejoice at having their child at home, many families have difficulty in adjusting to the transition from hospital to home; (c) while full-time nursing care at home is valued by families and the support is greatly needed, families also feel that their privacy is invaded; (d) once a child is cared for at home, social and psychological support are needed for both children and families; (e) the needs of the child and family may change over time; and (f) the financial strain of caring for a ventilator-assisted child at home can be overwhelming for the family. Overall, the findings indicated that the responsibility of caring for these children at home impacts greatly on the family. While most families want to have their child at home, it comes at a great cost, both psychologically and financially.

Using the same population, Wegener and Aday (1989) used a cross-sectional methodology to identify predictors of family and caregiver stress in caring for ventilator-assisted children at home. Data from parents caring for 121 ventilator-assisted children at home were used to develop a profile to help predict families at risk for stress.

Specifically, the profile of a family at risk incorporated three categories of significant predictors: family finances, family structure and social environment, and comprehensiveness of discharge planning. Similar to Aday and Wegener's (1988) study, within these indicators, the most powerful predictors of caregiver stress and family impact were those related to family finances. Therefore, awareness of these predictors of family stress is critical in assisting nurses and other health care professionals as they prepare families for home care with children needing assisted ventilation.

At least three research teams have used a qualitative perspective to examine the impact of caring for children needing assisted ventilation. One study collected qualitative and quantitative data to explore parental views about caring for these children (Noyes et al., 1999), another study focused on the medical, financial, and psychosocial needs of children and their families (Scharer & Dixon, 1989), and a third study explored the experiences of caring for children dependent on assisted ventilation from the mother's perspective (Wilson et al., 1998). Since the participants were not limited to responding to specific questions or choosing specific options, the qualitative studies provided rich descriptions from both the parents' and mother's perspectives of caring for their children at home.

In the most pertinent of these three studies, Wilson et al., (1998) used a grounded theory methodology to examine the experiences of mothers caring for their children needing assisted ventilation. A total of 32 interviews were conducted with 16 mothers to identify the key variable of absolute involvement, which was fundamental in describing the commitment that the mothers displayed when providing care to their child and family

on a daily basis. The attributes of mothering (resources and constraints), meeting the demands of caregiving, and employing strategies of care represented the experiences of the mothers. The researchers described the mothers' resources, which included using home care resources, trusting in their religious beliefs, relying on informal supports such as family and friends, taking part in social activities that included all family members, and having other children. The constraints on the mothers which included providing home care, meeting family demands, providing financial and nursing services, and needing hospitalization are comparable to findings in the studies by Aday and Wegener (1988), Quint et al., (1990) and Wegener and Aday (1989). The mothers in Wilson et al.'s study felt that in order to provide effective and efficient care to their ventilator-dependent children, the strategies that were required to meet care demands were adjusting to the struggle, reframing time, staying in hospital, making sense of realities, facilitating family life, expanding caregiving, and refusing to give up.

Similar findings were found in a qualitative study by Scharer and Dixon (1989), that explored the management styles of 10 families, five of which had a ventilator-dependent child at home and five of which had a child who was hospitalized. Results of the study identified three management themes: resources, barriers, and parenting. Resources included significant others, health care personnel, sources of financial assistance, and systems such as schools, hospitals and home care agencies. Maintaining support systems and advocating for the best interest of the child were strategies utilized by parents to aid them in managing resources. The barriers to successful management of the family's situation included the health care system and/or health professionals, other

bureaucratic systems, and financial difficulties. Strategies that were developed to assist in parenting their children included the sharing of responsibility for the child's care, comparing themselves with others, taking things one day at a time, trying to define the child's future, and trying to treat the child as normal as possible.

A questionnaire to collect both qualitative and quantitative data on the experiences and views of seven parents managing children dependent on assisted ventilation in the United Kingdom was used by Noyes et al. (1999). While the study has limitations such as the use of a survey design versus face-to-face interviewing, the findings are noteworthy. Four themes were identified from the open-ended questions. The first theme, *Effect of hospitalization on child* was related to the parent's perception that spending a prolonged period of time in hospital had a negative effect on the child in terms of development, particularly in relation to communication skills and concentration. *Nursing and social support at home* was in relation to the inconsistencies in the home care supports provided for the parents. The health care authority the parents were under determined the amount of nursing and social support that the parents received. For example, the number of hours provided to the parents ranged from zero hours of nursing and domestic care to 24 hours of nursing care as well as two hours of domestic care. However, the study does not indicate how parents organize the care of their children at night when they are fully ventilated. *Discharge home: Lack of co-ordination and follow-up* expressed the parents concerns regarding lack of nursing and social support at home prior to discharge. Once the children were discharged home from the hospital, parents noted that they were not given regular appointments and there was no sharing of long-

term goals. The final theme, *Holidays*, related to the parent's descriptions of being able or not being able to take a vacation. After careful planning, two of the seven families were able to plan a vacation out of the country, four could plan a holiday within their home country, and one child was still in hospital, but in the process of being discharged. All three of these studies indicate that the impact on families of caring for a technology-dependent child is considerable.

Summary of the Literature

In light of the increasing numbers of technology-dependent children being discharged from the hospital to home environments, there is a paucity of research specific to this population, especially on the experiences of the mother. Many of the research studies reviewed here were quantitative and cross-sectional in design, although qualitative research is beginning to emerge with greater consistency in the literature. A comprehensive review of the literature has verified that there are a number of financial, psychosocial, and psychological factors that can affect families caring for technology-dependent children. In addition, studies have focused on the lack of support systems such as respite care and community supports. As well, research in this area is only beginning to explore the complexities of living with and caring for a technology-dependent child at home.

With advances in technology, it is likely that the number of children requiring technology, including mechanical ventilation will increase, but their care requirements remain complex and have not been well documented. In addition, many studies subsume

the mother's perspective in caring for a technology-dependent child in the framework of the entire family system. Consequently, the impact on the family, especially mothers, of providing care to technology-dependent children is only beginning to emerge. Therefore, further research using a qualitative approach is required to understand the impact of the child's needs and their effect on mothers. While the previous studies support the recognition that caring for a technology-dependent child at home poses a stressful situation for families, more qualitative studies are needed to present a more complex and multidimensional view of the mothers' lives. Only in hearing their uninterrupted stories and allowing them to create their own meaning from the experience and the telling of their experiences, as phenomenology allows, are we to fully understand their life situations, needs, and desires. In addition, more extensive qualitative research would provide deeper knowledge about the phenomenon of families caring for technology-dependent children. For this reason, I employed phenomenology as the methodology to gain an understanding of the experiences of mothers caring for ventilator-dependent children.

As previously noted, only one current study explored the experiences of mothers caring for their ventilator-dependent children at home (Wilson et al., 1998). These researchers emphasized the importance of nurses being knowledgeable and insightful about the effect of caring for ventilator-dependent children on family members. Only in doing so will nurses be able to help families meet the daily challenges that they encounter with complex technology at home. Furthermore, the study advocates continued research

in this area emphasizing the benefits such research would have for mothers caring for children affected by technology.

This thesis will expand on Wilson et al.'s work by using phenomenology as the research methodology. My intent was to provide the opportunity for these women to speak at length, and in depth, about the fullness of their experience, and to allow them to create their own meaning. The key player in managing high-technology care at home is the family, and in this study, the mother. Without a willing family, these children would most likely remain in an institutional setting and never experience life within a family unit. It is imperative therefore, that a body of literature is established to create a base of knowledge regarding high-technology pediatric home care. As professionals, not only do we need to be well informed about what we are asking families to be responsible for when we prepare families for their child's discharge to home, but we must also be knowledgeable about, and inform families what their daily experience will be like in the days, months, and years ahead.

CHAPTER 3

METHODOLOGY

Phenomenology was selected as the method to understand the nature of the experiences of five mothers who have the day-to-day responsibility of caring for their ventilator-dependent children at home. In this chapter, I will present an overview of phenomenology as a methodology and as a mode of inquiry as described by van Manen (1990), and will then describe how I used this phenomenological method to investigate the experiences of mothers who care for these children on a daily basis.

Phenomenology

Phenomenology is both a philosophy and a methodology that was originally described by Edmund Husserl who recognized human experience as a unique source of knowledge. Grounded in Dutch and German philosophic traditions, van Manen's (1990) text serves as a guide for pursuing human science research that is both phenomenological and hermeneutic. van Manen makes a distinction between phenomenology and hermeneutics by noting that phenomenology is the description of lived experiences, and hermeneutics is the interpretive study of these descriptions. Phenomenology is based on the assumption that all realities are subjective; that is, each person interprets and gives meaning to the facts of the world (Boyd, 1993). The overall goal of phenomenology is to construct a description of human actions, behaviors, intentions, and experiences as they naturally occur in the lives of the research participants. Through hermeneutic reflection,

the researcher interprets the meaning of the research data and achieves a greater understanding (van Manen).

van Manen's (1990) research method clearly articulates the interrelationship of phenomenology and hermeneutics through a process of textual reflection that contributes to understanding practical action. As outlined by van Manen, this method involves a dynamic interplay among six research activities: (1) turning to a phenomenon of interest, (2) investigating the experience as it is lived, (3) reflecting on essential themes that reflect the phenomena, (4) describing the phenomenon through the art of writing, (5) maintaining a strong and oriented focus on the phenomenon, and (6) balancing the research context by considering parts and the whole. The remainder of this section will describe how I incorporated these six research activities to understand the experiences of mothers who have children dependent on ventilators.

According to van Manen (1990) phenomenology begins when the researcher selects a phenomenon of interest and commits to an aspect of human existence so that the lived experience can be fully explored and understood. Specifically, this step involves formulating a phenomenological question and explicating assumptions and presuppositions about the phenomena being studied. In this study, I turned to the phenomenon of being the mother of a child dependent on mechanical ventilation. Having worked in a pediatric intensive care unit for 17 years, I am aware of the complexity of care that is required for this particular group of children. I am also aware that limited research had been conducted regarding the maternal experiences of caring for these children. Therefore, I have a strong interest in understanding what it is like for mothers to

care for their ventilator-dependent children at home on a daily basis. How is a mother's life affected when they learn that their child needs a ventilator to survive? How do they adjust to the changes in their lifestyles? How do they learn to cope with all of the equipment that they must learn to work with and be responsible for? What are the challenges that the mothers face on a daily basis? Are there concerns about the future? In this study, my aim was to gain a deeper understanding of the mothers' experiences caring for a child who needs a ventilator to survive.

Prior knowledge about or experience with the phenomenon under investigation can be problematic for researchers as it can lead the researcher to make presuppositions or assumptions about the phenomenon (van Manen, 1990). To alleviate this problem investigators are encouraged to put aside or bracket any pre-existing knowledge or assumptions about the phenomenon (van Manen, 1990). Despite the fact that bracketing has been considered to be one of the key concepts of the phenomenological method of inquiry, van Manen questions whether or not it is possible for researchers to really put aside their knowledge about the subject. He suggests that rather than setting aside what we know, we should be aware of whatever knowledge and beliefs that we have regarding the phenomenon under investigation. He notes that if we try to forget what we already know about the experience, we risk having our presuppositions re-surface into our reflections about the experience. Therefore, for this study I reflected on my personal interactions and professional experiences with mothers who have children dependent on a ventilator. In doing so, I became more conscious of any biases or presuppositions I may have which enabled me to keep them at close range throughout this investigation.

The second research activity that van Manen (1990) described is “investigating the experience as we live it rather than as we conceptualize it” (p. 30). This activity involves becoming absorbed in the phenomenon to ensure that an understanding of the lived experience is achieved. Rather than take anything for granted van Manen cautions researchers to approach the investigation with the belief that the meaning of the lived experience “needs to be found” and “if all presuppositions are suspended”, then it will be the lived experience that will remain (p. 53).

van Manen (1990) suggests that interviewing, writing, and observation are approaches that can be used to collect human science research data. For this study, I collected data through the utilization of unstructured interviews with mothers of children who need mechanical ventilation. Being a novice researcher, I felt that an interview guide, while not using it in a structured manner, would assist me in ensuring that the interviews were as complete as possible (see Appendix A). In phenomenological research, the interview has two purposes. First, the interview is a way of data collection that enables the researcher to grasp deeper meaning and understanding of the phenomena. Second, it can be beneficial as dialogue between the researcher and the participant in relation to the meaning of the experience. While I was aware of both of these purposes during my study, it was the first purpose that I focused on when I was interviewing the mothers about their experiences with caring for their children. In doing so, I was able to understand more fully what the lived experience was like through the rich descriptions that was described by the mothers. Following each interview, my thesis supervisors

reviewed the interview transcripts and gave me constructive feedback on my interview approach in relation to the style and quality of the data.

van Manen (1990) describes the third research activity as “reflecting on the essential themes which characterize the phenomenon” (p.30) to try and identify essential meaning. He believes that when the researcher reflects on the lived experience under study, she/he is attempting to establish what it is that gives the particular experience its significance; what makes the experience what it is. To arrive at this understanding, the researcher must conduct a thematic analysis to reveal the essential structures in the data. These themes give shape to and describe the content of the experience. It should be kept in mind, however, that themes never completely capture the deep meaning of an experience. They are “at best a simplification...an inadequate summary of the notion” (van Manen, p.87).

In phenomenological research data collection and analysis occur simultaneously. Therefore, at this point in the research process, I reflected on the data that were gathered from the interviews with the five mothers who care for their children dependent on mechanical ventilation. My goal was to explore the significance of this experience from the mothers’ experience. Following each interview, I listened to the tape to begin the data analysis process. Each audiotaped interview was transcribed verbatim. Reading the transcript several times while listening to the audiotape ensured that the tapes had been transcribed accurately and this enabled me to gain a deeper understanding of the mothers’ experiences. In addition, I was able to identify potential themes that emerged from the data. Throughout the entire process, I remained cognizant of my own beliefs and

knowledge and attempted to separate them from my interpretation of the data in order to reflect on the data in a critical manner.

The specific approach that I used to begin the data analysis was van Manen's (1990) selective or highlighting approach. The text was read and reread to select specific statements that appeared to be essential in describing the mothers' experiences. I took each of the highlighted statements and began to capture them in writing. As the data analysis continued, and having compared and contrasted the identified themes from the interviews to allow commonalities and differences to become apparent, I identified the themes from the transcriptions that described the mothers' experiences of caring for their children dependent on mechanical ventilation.

Once the themes have been identified, the researcher describes the phenomenon through the art of writing and re-writing. van Manen (1990) claims that, to do research in a phenomenological sense, is always "a bringing to speech of something" (p.32). In order to capture the essence of the experience in writing, the researcher must be sensitive to the subtle undertones of language, be a true listener and able to listen to the way the things of the world speak, and then use language to allow these things themselves to speak to the reader. For this study, I began the process of writing after the essential themes had been validated. From the interview transcriptions, specific quotations were used to illustrate the participant's thoughts and feelings, and to enhance my own interpretation of the data. Through writing and re-writing and ongoing discussions with my thesis supervisors, I gained a deeper understanding of the developing themes. The themes were fine-tuned and

re-worked until it was felt that I had portrayed an accurate description of the lived experiences of mothers who care for their ventilator-dependent children at home.

The fifth activity describes that the researcher must maintain a strong and oriented relation to the phenomenon of interest (van Manen, 1990). While conducting the research van Manen notes that there may be temptations to get side-tracked or to settle for preconceived ideas and opinions. Furthermore, he stresses that the researcher must resist settling for superficialities but rather, must remain focused on the fundamental question or issue at hand. During this study, I maintained a strong and oriented relation to the phenomenon of children dependent on mechanical ventilation. As noted earlier, I am genuinely interested in the nature of this experience from the mother's perspective who provide the intensive care that is required for their children on a daily basis. Through the writing and re-writing of the text and from continuous feedback from my supervisors, I was able to illuminate the mother's experiences.

Finally, the researcher must balance the research context by considering both parts and whole (van Manen, 1990). In conducting phenomenological research, there is a danger that the researcher may get so caught up in the writing that she/he loses sight of the main goal which is to "construct a text which...aims at a certain effect" (van Manen, p. 33). While van Manen stresses the importance of having a clear research plan such as envisioning how the study will proceed and how the text will be organized, he also cautions against getting caught up in writing the particulars of the methodology until the study has been completed. In essence, the details can be established as the research proceeds.

Methods

According to van Manen (1990), methods are a mode of inquiry that allows the researcher to gain an understanding into the nature of the phenomenon. In my study, data were analyzed following five interviews with mothers who provided care at home to their children dependent on mechanical ventilation. This section describes the criteria for participation, data collection, setting, procedure, data recording and analysis, ethical considerations, and credibility.

Criteria for participation. Permission to conduct this study was obtained from the Research Proposals Committee, Health Care Corporation of St. John's, NL, to recruit participants through a local pediatric centre (see Appendix B). I also contacted a nurse manager at a local Pediatric Intensive Care Unit (PICU), who agreed to act as an intermediary in contacting potential participants who met the inclusion criteria. The participants in this study were mothers in the province of Newfoundland and Labrador caring for ventilator-dependent children at home who were recruited from a local PICU. The study participants met the following inclusion criteria: (a) have a child who is ventilator-dependent, (b) are able to give informed consent and understand the interview process, (c) live within the province of Newfoundland and Labrador, (d) are 19 years of age or older, and (e) can speak and understand the English language. A letter was given to the intermediary that clearly outlined the study purpose and method of data collection in order to ensure that the same information was given to all potential participants (see Appendix C). The intermediary contacted all of the mothers who have ventilator-

dependent children in the province of Newfoundland and Labrador and informed them about the study, established their interest in participating, and sought permission for me to contact them. The names and telephone numbers of the five mothers expressing an interest in the study were forwarded to me. I then contacted the mothers and explained the study in greater depth. As well, I clarified any questions or concerns the potential participants had with regard to participating in the study. The five mothers unanimously expressed an eagerness to participate in the study. After receiving a verbal agreement, an interview time and setting were scheduled. Participants were given the choice of being interviewed in their home, my home, by telephone, or at a location of their choice. The interviews were conducted in private and at a time when the participants did not need to be directly responsible for childcare (e.g., child was at school, resting, or being cared for by a qualified support worker).

Data collection. Interviews were conducted after the initial contact had been made with all of the participants and the written/telephone consent had been obtained. At the time of the first interview, the written/telephone consent forms were signed (see Appendix D). The interview approach was intended to obtain each mother's thoughts and feelings as they related to her experience with caring for a ventilator-dependent child at home. Specifically, what was it like to care for these children on a daily basis?

Data were collected using an unstructured interview format (see Appendix A). Interview questions were based on sections outlined in the literature review, my clinical experience, and facets of experiences associated with phenomenological research (van

Manen, 1990). Participants were provided with the opportunity to describe their experiences and to expand on them. Furthermore, I used questions from the interview guide to prompt or clarify statements and/or to facilitate verbalization of the participants' experiences. Periodically, during each face-to-face interview, I made notes that later assisted with the thematic analysis. Interviews were completed when the participants had exhausted their description of the phenomenon.

Two separate interviews were carried out with each participant. The purpose of the second interview was to validate the thematic findings. The first interviews ranged from 45 to 90 minutes; the second interviews ranged from 20 to 30 minutes. The audiotapes were transcribed for data analysis following each interview. The time frame for data collection was four months.

Setting. All of the interviews were conducted at a time and place that was convenient for the participants. Two interviews were conducted face-to-face; one interview took place at my home and one was conducted in a participant's home. Three interviews were conducted by telephone. The environment of the room for each face-to-face interview was quiet and the interviews were carried out without interruptions.

Procedure. Prior to each face-to-face interview, the participant was provided with an overview of the study. I also reviewed key aspects of the study (i.e., purpose of the study, length of the interview, and data collection techniques such as audiotaping and note taking), answered questions, and determined whether the participant wanted to

continue with the study. After I obtained the participants' written consent, the interviews, which were audiotaped, commenced.

Following the procedure as outlined by Morse and Field (1995, p. 55), I attained telephone consent from the participants who were to be interviewed by telephone. Initial contact was made with each participant. Again, each participant was presented with an overview of the study and I reviewed key aspects of the study (i.e., purpose of the study, length of the interview, and data collection techniques such as audiotaping). The participants were asked to choose a time, date, and a private place without interruptions to conduct the interview. Prior to the interview, I ensured that the participant was ready for the interview and reminded the participant that the conversation would be audiotaped. I further explained that it was required that the participants provide formal consent to participate in the study. An explanation of the study was read to each participant. A recording was made of the consent statement being read, followed by the participant's responses. As well, a copy of the consent form, a written information sheet explaining the topic, listing the title of the study, the name of the investigator, contact address and telephone number was mailed to participants for their information. Having obtained the participants' permission, the interviews, which lasted 45-90 minutes, were audiotaped. In addition, I obtained permission from all participants to make contact by telephone if questions or the need for clarification occurred.

A second interview was arranged with all participants following the transcription of the first interviews and initial thematic analysis. Before the follow-up face-to-face and telephone interviews, each participant had been given sufficient time to read the

interpretative summary that I prepared from the first interview and each participant was asked to confirm its accuracy. All of the participants confirmed that the summary accurately described their experiences of caring for their ventilator-dependent children and no new themes were identified.

Data recording and analysis. Following each interview, the audiotapes were transcribed verbatim and coded. In addition, nonverbal information was documented following each face-to-face interview. This allowed me to understand the emotional tone of the data. Each transcript was read and reread to ensure accuracy, and to enable me to become immersed in the data. The selective or highlighting approach as outlined by van Manen (1990) was used to reveal the thematic aspects of the phenomenon and to facilitate an understanding of the participant's experiences. Through the reading and rereading of the text, I underlined specific statements or phrases that captured the meaning of the mother's experiences in caring for their ventilator-dependent child. As noted by van Manen, to engage in critical reflection of the data, bracketing is required in order to accurately "study the essential structures of the world" (p.175). Therefore, I made a conscious effort to bracket all feelings, thoughts, preconceptions, and beliefs regarding the phenomenon under study.

Reflection on the meanings that came from the text aided me in sorting through the information obtained from each participant. This helped me to separate the minor themes from the major ones. As the interviews were completed, cross comparing started so that I could recognize the themes that were common for all participants. In addition, I

consulted with my thesis co-supervisors for feedback on the approach taken to develop the content of the interpretative summaries. Having agreed upon the process and content of the summaries, I arranged the second interviews.

Once the relevant themes were identified and interpretative summaries confirmed by participants, I began the process of writing a report on the findings. To assist in this process, I reflected upon my personal experiences of working with mothers caring for ventilator-dependent children in a clinical setting. I also reviewed notes taken during data collection and analysis, which provided insight into the lived experiences of the participants. Through the process of writing and re-writing, and in consultation with my thesis supervisors, I developed a greater understanding of the emergent themes. Eventually, the themes began to assume a unique, but interrelated form, with the written accounts closing into a hermeneutical interpretation of the text. van Manen (1990) describes this phase of the analysis as “The inscribing, the writing of the text *is* the research; it is the relic of embodied reflections” (p.129). I continuously appraised the text in terms of the significance of the themes for the total essence of the lived experience of mothers caring for ventilator-dependent children. Throughout the study, I periodically stepped back and looked at the whole – the phenomenological text and the research question it attempted to answer. In doing so, the essence of the lived experience began to emerge and assume a meaningful form.

Ethical considerations. In addition to seeking permission from the Research Proposals Committee, Health Care Corporation of St. John’s, NL (see Appendix B),

permission to conduct the study was also received from the Human Investigation Committee (HIC), Memorial University of Newfoundland (see Appendix E). Each participant was given a copy of the consent form with my name and telephone number on the form. Prior to beginning the first interview, I discussed the purpose of the study, the possible risks and benefits, the voluntary nature of participation, and the time commitments. Participants were informed that while they may not benefit personally from the study, the study would add new knowledge in relation to mothers caring for their ventilator-dependent children at home. In addition, I addressed questions or concerns raised by the participants. As well, they were informed that they could withdraw from the study at any time and refuse to answer any questions that I posed. I made every attempt to be sensitive to the participants' verbal and non-verbal communication. Other than using prompts and reflective techniques as necessary, I listened quietly throughout the interview. Periodically throughout the interviews, several of the mothers cried while describing their experiences with caring for their children at home on a daily basis. When the mothers were visibly emotional, the tape recorder was turned off to allow the mothers the opportunity to end the interview or to continue. Each mother expressed the desire to continue the interview as it was the first opportunity that they had been given to talk about their experiences. I displayed empathy toward the mothers during their emotional periods. The interviews ended when all of the mothers had exhausted their descriptions of their experiences, and no new information transpired.

I anticipated that the risks from participating in this study would be minimal. To avoid any potential negative effects, I used a non-leading approach and was sensitive to

the participants' discomfort while they discussed their experiences. All participants were encouraged to call me if they had any concerns or questions as a result of the information shared during the interviews.

Appropriate measures to ensure confidentiality of all data and to protect the anonymity of participants were also undertaken. Because the total number of children in this province dependent on mechanical ventilation for survival is small (seven), it may be easy to identify the participants and their children. Therefore, to further protect the anonymity of the participants and their children, the word [child] is used in the analysis section of Chapter Four to describe the experiences of the participants rather than using real or fictitious names or the term male or female. In addition, the participant's demographics and characteristics are not included in the writing of this thesis due to the strong possibility of identifying the mothers who participated in the study and their children. Given the fact that the mothers and their children had an affiliation with the only pediatric centre in the province of Newfoundland and Labrador for all of their health care needs put them at risk for easy identification. This was a concern for the mothers who agreed to participate in my study. I gave them a strong assurance that they would not be identified in any way. For this reason, I employed the above measures to respect their anonymity.

Audiotapes and transcribed data were also treated as confidential throughout the study. All audiotaped and transcribed data identified the participants by a code rather than by name. A list of participants' names and corresponding code numbers was secured in a locked filing cabinet separate from transcripts and audiotapes and to which only I had

access. All identifying information, including the audiotapes was destroyed following a review of transcripts for accuracy.

Participants were guaranteed that the information provided would be guarded with strict confidence and reports of findings would include grouped data or anonymous quotations. Members of the thesis committee were asked to review and discuss the initial interviews to provide feedback on my interview technique and to assist in identifying underlying themes. Participants were also informed that once the study was completed it would be available at the Health Sciences Library, St. John's, NL and it was likely that the thesis may be published. Once again, they were informed that their anonymity would be protected.

Credibility. In qualitative research, credibility is measured by how well the researcher reports the viewpoints of the informants (Morse & Field, 1995). van Manen (1990) notes that a qualitative research study is credible when the people having the experience under study recognize it as their own. To ensure the credibility of this study I endeavored to achieve it in several ways. I worked in close collaboration with two faculty members at Memorial University of Newfoundland, School of Nursing. Both committee members were proficient in phenomenological methodology and had a sound knowledge on the study area. Several meetings were held with the committee members that aided in the unearthing and enhancement of meanings expressed in the transcripts. Through the provision of feedback, my supervisors enabled me to gain a deeper understanding of the experiences and in extrapolating meanings. During the second interviews, the participants

in this study confirmed that the themes accurately reflected their experiences, thereby providing further validation of my findings.

CHAPTER 4

FINDINGS

This chapter presents an analysis of the research findings relative to the experiences of five mothers caring for their ventilator-dependent child at home. In analyzing the transcribed interviews the following themes were identified: taking charge, “full time nurse, part time mom;” loss of personal freedom; forgotten mothers of forgotten children; and thinking about the future. Although presented separately to emphasize different facets of the lived experience, the themes are interdependent.

Taking Charge

Taking charge was a theme that was evident throughout the data, and one that became increasingly evident in the lives of the mothers as they managed the care of their ventilator-dependent child. The enormity of the child’s health problem and the eventuality of death was devastating and challenging for all the mothers; yet somehow they had a sense of their responsibility in the situation and the need not to be overcome by it, but rather to master it and to take charge. In reflecting on their experiences, all of the mothers started their story with the birth of their child and the health problems with which they were diagnosed. In telling about their experiences, the mothers indicated that they waited as long as two to four years before a diagnosis was confirmed for their child. Before being discharged to home, all of the children had spent several months to three years in hospital. At first, the mothers hoped that their child would “get better.” However, they realized that mechanical ventilation was needed in order for their child’s survival

and this enabled the mothers to take charge of their situation, starting with accepting as best as they could what had happened to their children, and then moving on to provide the best care possible for their children at home. Accepting that their child was not going to get any better took longer for some mothers than others. For example, one mother lived in hope that her child's condition would improve because "everyone said she was going to get better." With time, however, her child's condition became progressively worse, and she needed to feel that she had some control or mastery of the situation to prevent it from victimizing her. She realized that she first had to accept the situation. She explained her acceptance in this way:

...the hardest, hardest part ...looking at [child] and knowing [the child] is not going to get any better. It took us a long time to accept that [child] wasn't going to get any better. All I can say is that parents learn to accept it, and unless you're in that shoe, you'll never understand how you can learn to accept something like this...but you do...and you just do everything [you] can for them.

The mothers also took charge by developing organizational and managerial skills through monitoring the ventilator-dependent child's status, keeping a watch on the performance of the respite care workers, overseeing all medical and nursing interactions with their child, and ensuring that all of the children's supplies and equipment were available. Even though they had respite care workers who assisted them, the mothers were ultimately in charge of their children's care. Some of the mothers rarely used their respite care workers because they preferred to care for their children themselves. Taking charge also meant keeping the needs of other family members in perspective. Mothers who had other children were determined not to let the needs of their ventilator-dependent

child interfere with the needs of their other children. One mother was adamant that her other children would not be responsible for the care of their ventilator-dependent sibling.

She expressed her beliefs in this way:

Ten years ago, I told my [children]...your life is gonna go on normal. You'll never be involved with any of [child's] care if I got anything to do with it. You can help out, you can volunteer, you can read to [child], and you can help [child] to bed ...you're not gonna be held responsible...and this is why they coped with it fairly well, because I didn't throw any responsibility on them.

Taking charge of their situation was also evident in how the mothers advocated on behalf of their child because if they didn't do it "no one else would." Since the mothers were the experts in the care of their ventilator-dependent children, they could readily identify their child's needs, and tried, sometimes in vain, to keep the best interests of their child as a priority. As with many other aspects of caring for their ventilator-dependent children, advocacy was a continuous process for many of the mothers. The mothers tried to locate appropriate resources such as extra respite care, to find extracurricular programs in which their children could participate, and merely see what resources were available for their children should they choose to move out on their own when "they came of age." However, the mothers felt frustrated in their efforts because no one seemed to have an answer to their questions. One mother shared the following:

...the numbers are small here...with regard to the number of children in the province who are home on ventilators and I feel that the government doesn't realize the...care that goes along with caring for those children at home. We don't have enough people to, I guess, fight or advocate for those children at home.

Moreover, in taking charge of their situation, the mothers became more assertive in their advocating role on behalf of their children. Prior to their children's illness, many of the mothers noted that they would never question medical personnel or other health professionals. Now, they felt the need to go that extra mile to ensure that their ventilator-dependent children got what they deserved. One mother stated: "For one thing, before all this I wouldn't question things, especially medical...now I do. If I feel I should be gettin' something and I'm not, I'll push it until I gets it." Another mother shared her thoughts in this way:

Sometimes, you gotta be assertive, and I'm sure...that's a skill I've developed over the years as well...to be a little bit more assertive in terms of, like you know, pushing...I need to have this done, as opposed to okay, I'll wait. Sometimes you have to do that, especially when you're looking after a child like [child].

In addition to advocating for the ventilator-dependent child, some of the mothers advocated on behalf of their family. They became more skilled at articulating their need for extra hours of respite care in order to maintain family stability.

Through taking charge the mothers created a new "normal" by adapting to a new and different way of living, and by reexamining their beliefs and values. Although the mothers in this study viewed their families as different from those who did not have a ventilator-dependent child, they adjusted to a lifestyle that included their ventilator-dependent child, and essentially accepted their life as a "normal" life for them. The mothers were very matter-of-fact in telling about their everyday lives. One mother described how frightened she was when she visited her child for the first time in an Intensive Care Unit (ICU). The sound of alarms and the sight of the equipment, the

multitude of tubes, pumps, and so forth were foreign to her, but with time the ICU became a routine part of her daily existence. She spoke about how over time caring for her ventilator-dependent child has become such a “normal” routine for her, that “other people’s lives seem abnormal to me now.” For example, doing her child’s care such as maintaining the ventilator, doing tracheostomy care, connecting oxygen, administering medications and feedings, are normal procedures for this mother; on the other hand, what most people view as normal activities such as watching their “nephews/nieces walking around the house” and developing age-appropriate motor skills appeared abnormal to this particular mother. Her view of normal child development was affected by her experience of her own child’s development.

In taking charge, the mothers were boosted by their own competence in their ability to meet their child’s needs, and despite their negative or frustrating incidents related during the interviews, they were able to identify positive aspects of caring for their ventilator-dependent children. Several of the mothers felt that the experience of having a child with such intensive needs contributed to personal growth and made them stronger as individuals. A mother shared this perspective:

Havin’ a child like [child] changes your outlook on things. I think I’m calmer...got more patience...looks at things different. Having [child] has brought many challenges, but it has made me stronger.

The mothers noted that maintaining a positive attitude was an important dimension of taking charge of their situation and in making mechanical ventilation “fit” into their daily lives. One mother reflected: “Having a child like this makes you realize that...no matter what package you are given in life you can handle anything if you have a positive

attitude.” However, at times the mothers displayed impatience toward other individuals who did not understand their situation. One mother felt “irritated” as she reflected on how the views of society regarding physically and mentally challenged children conflicted with her beliefs and values about caring for her ventilator-dependent child:

I’ve been around people [who] say, if they know a child like [child’s name], and you know, their life is not worth nothing, they’d be better off not here, and that irritates me...I think you got to be in someone else’s shoes to know what is and what isn’t good for them. Well, I look at other people, and it’s just that I see, ah how they act sometimes...they get mad with their child for nothing really...I think if they can’t handle a normal child, how could they handle someone like [child]? Sometimes I get mad with God, but then I see something like that and I figure we were given [child] for a reason. I don’t know if [child’s] aware of anything, but we can kiss [child] and love [child], and [child] is our life.

Yet, they seemed to accept, at least to some degree, the situation that they and their families were in. They grew in their ability to be with the child and to love and accept him or her, although they still knew the limits of their situations. Their mastery of their situation enabled them to put their child’s illness in perspective.

“Full-Time Nurse, Part-Time Mom”

Due to the intensive and skilled care that is required to provide the ventilator-dependent children with exceptional care, the mothers noted that they spent more time doing nursing duties than they did parenting. Given the tremendous amount of responsibility that is involved in keeping the children alive, one could easily understand why the mothers felt that they are a full-time nurse and a part-time mom. Before the child was discharged to home, three additional people had to receive training on how to care

for him or her. Those typically trained were family members such as a spouse, partner, grandparent, aunt, or sister. Caring for each of the five children involved not only ventilator care, but also the responsibility for oxygen therapy, gastrostomy tubes, nasogastric tubes, enteral nutrition, tracheostomies, medications, and the physical care such as bathing. With the exception of one child, all of the children required mechanical ventilation 24 hours a day. One mother gave this account of the extensiveness of the nursing care provided and the initial fears that she experienced:

This wasn't kids' training...you're talking about ICU training... a child on a ventilator...trachs had to be changed...all new to me...the meds, the medical part of it all...that wasn't something I was familiar with...I mean, all this was very scary. Will I be able to maintain [child], heck, would I be able to keep [child] alive...you know, the kind of intense care that's involved. What if something happens?

For some of the mothers, bringing the child home was both exciting and full of fear, especially since it meant a severe curtailment of activities outside the home. One mother commented that there “was so much excitement, yet deep down inside the fear was killin’ it all.”

Bringing their ventilator-dependent child home required much dedication and commitment from the mothers. At first, all mothers except for one stayed at home to care for their child. Staying at home was a choice the mothers made because they personally wanted to provide the care. Three of the mothers were recipients of social assistance prior to the birth of their child and because of the level of support required for the child once they went home from hospital, they were unable to work outside of the home. The mothers who received social assistance wished they did not have to receive it; and one

mother noted that if she had her time back, she would have “gotten a career.” The same mother expressed: “I should have become a nurse” because “I certainly play the part every day, I just don’t get paid.” Another mother who reflected on her years of doing more nursing care than parenting stated:

I’m to the point now, and I have been for the past year or so ‘cause it’s been difficult dealing with [child’s] dad and...trying to work, just trying for some self respect and...just to be working. I never did wanna be on the Social Services program. Never, did I dream I would have to be stuck on it because of a child. And it was like...I’d go to school half asleep in the mornings. But when I got there...I felt good about myself. I’m doing this for me. And for [child] to some degree, but it was more for me...to make me feel whole, make me feel like a person. and not a nurse, a full-time nurse and part-time mom... that’s all I’ll ever be... ‘cause you’re doing more nursing than you are parenting.

In the beginning, two of the mothers chose not to leave their child in the care of others, as they did not trust anyone else to care for their child. Having mastery over the situation initially meant doing everything alone. All of the mothers admitted that they were the primary caregivers for their child. While most of the mothers were very complimentary towards their spouse in that they were “good providers” and helped out with the care such as lifting, there was still an acknowledgement that they, as mothers, had the primary care-giving role. As one mother affirmed, “[Husband] has his job, so he’s able to take his mind off, you know, through other things.” Another mother, while praising her husband for being a good father also noted that because she couldn’t rely on him, she often felt resentful. She stated: “He’s so much involved in his work and business, that ...where’s the time for [child]? And where’s the time for me?”

In this study, the mothers felt alone in caring for their ventilator-dependent children at home and this enhanced their feelings of being split between being a full-time nurse and a part-time mom. They took on the responsibility in all aspects of their child's care such as advocating on their child's behalf, calling physicians, community health nurses, social workers, and other health care providers when issues occurred pertaining to their children. They noted that over time, growth in knowledge and competence assisted them to be less fearful as they paid attention to any subtle changes in their child's condition. They acted on it immediately to prevent a medical crisis from erupting. For example, they took it upon themselves to call a physician at the pediatric centre when their child needed medical attention. One mother spoke emotionally about how time and experience with caring for her child at home has helped her "to act quicker" when her child becomes ill. She stated:

The first three weeks, we never slept at all...we were really nervous, because they told us they didn't know [child's] prognosis. Every time that [child] takes sick, we were really upset...we'd take [child] to the hospital...we didn't know if [child] was going to make it. A couple of times, [child] collapsed in the ambulance. but...for the past couple of years...we deal with it ourselves...we know when [child's] getting' sick...by the way [child] acts and by the way [child] has more secretions...temperature...so we get antibiotics in [child] right away...so you act quicker when [child] is ill, and when [child] can't keep the feeds down, we know that we got to bring [child] in [to hospital] right away. So we call the [pediatric centre]...then we go on with [child].

Fulfilling the role of a full-time nurse and part-time mom was further reaffirmed through the mothers' acknowledgement of the amount of care that their children needed and that providing the care at home was optimal for their survival. The mothers were quick to point out that their family, especially the ventilator-dependent child, came first.

As one mother stated: “[Child] is our life now.” This level of responsibility was recapped by another mother who noted that “the mother has...you know has to be there for everybody.” This self-sacrifice, however, had its toll on the participants’ sense of self-identity and the realization that their own needs were often neglected. One mother presented this perspective on the impact of caring for her child:

Things haven’t been easy...to the point where there’s times I’ve almost walked out. I got so frustrated that you can’t have a quiet hour...you come out of a stressful day...you come home and I gotta go in and see to [child], you know, how was [child] today? Or how was school? ...and what about [child’s] meds? ...what about supplies? And what about [child’s] bowels? It seems like you have no time for yourself. These years in a woman’s life should be, you know, a time to relax...it’s more stressful for me...

In taking on the role of a full-time nurse and a part-time mom another mother found that she lost all interest in everything once [child] got sick. She recalled that before her child was born, her career, outings such as barbecues and socializing with friends was a big aspect of her life. However, since her child was born, [child] has required 24 hour nursing care, and the mother has given up everything else that was of importance to her. She reflected on her life at present:

I have no interest in nothing. [Husband] has no interest in nothing. Everything is based around [child]...there isn’t anything else in our lives right now...there’s nothing the same about our lives.

The women lost contact with the friends they had before their child was born. There was also a fear of making new friends because they may not “understand” the child’s condition. For almost 20 years, one mother has been consumed with playing the part of a

nurse in caring for her child and the thought of something happening to the child is something this mother cannot think about. She stated:

For almost all my adult life, it's been [child]...I was only 25 when [child] was born...I try not to think about it, you know, that you've given up anything else of any interest in you life. I can't deal with anything happening to [child]. I know [child] can die anytime, but I try not to think about it.

The reality that their lives are split between being a mom and being a nurse has had a toll on the mothers. They have sacrificed greatly, knowing that the care they provide, whether routine parental care or intensive nursing care, is essential for the quality of life of their child.

Loss of Personal Freedom

Each mother expressed considerable emotion about the personal impact of caring for her ventilator-dependent child. Despite the commonality of the experience, however, the mothers were unique in how they experienced the loss of freedom.

When asked to express what it was like to care for a ventilator-dependent child at home, the mothers invariably stated that it was hard and challenging. One of the most difficult and problematic aspects identified by the mothers was their "loss of freedom." One mother expressed it this way: "It's not as much the physical or the work of the ventilator, it's the loss of your freedom, and I'll always be honest about that, because you really can't go anywhere." The mothers talked about how they had lost the freedom to come and go as they pleased and that their lives revolved around a schedule. As described

by several of the mothers, a simple trip to the grocery store was sometimes a major endeavor. One mother captured the feelings of other mothers in this way:

It was hard. I couldn't go nowhere 'cause there was no one to look after [child]. I wouldn't leave [child] with nobody. Even to go to the store was a major thing...especially first when we came home, we took [child] with us...with the oxygen tubes and that, it could be two hours before we were ready to go.

Loss of freedom for the mothers was further reflected in the loss of free time and in the loss of contact with their friends. As related by one mother, the giving up of free time was a difficult thing to adjust to. She stated: "Giving up time...I had a hard time with that one." The mothers seldom socialized outside of their home and if they did, they were always "on a schedule." Yet, while they felt that their freedom had been jeopardized, all of the mothers were strongly committed to their child. One mother described her experience in this way:

I lost contact with most of my friends...we never went anywhere...and that was fine. When you are carin' for a child like [child] you have to give up a lot. You really do become isolated from everything else...this becomes your life. You live with it every hour of every day.

Other mothers articulated that while they often felt "left out" and "let down" by not being able to participate in activities that most people take for granted, such as going for a walk, getting a hair cut, or simply joining a friend for lunch, having their child at home was more important. The mothers accepted that caring for their child at home was "their life now," and they were willing to make the sacrifices, despite occasionally feeling sad and depressed about the impact of their loss of freedom. One mother summarized it in this way:

...like going for a walk is ...a big event for me. You know, things other people take for granted. I try not to...let it get me down, but sometimes it does. But I know I have to keep going for [child]...[who] is my life.

One mother who felt alone was not free to do anything but care for her ventilator-dependent child for the first two years after taking the child home. After two years and due to a permanent separation from her partner, during which she had contact with a social worker, she was informed that respite care was available. One wonders if this mother would ever have known, or how long it would have taken, for her to determine that respite care was available, if she and her partner had remained together. Respite care was provided when the mother and her partner separated and “social services stepped in to...give me 15 hours a week.” Like other mothers in this study, this woman felt totally responsible for the care of her child and very removed from the world outside her home. She noted that while her friends had moved on with their lives, hers totally revolved around her child; in her words, “your life becomes the child.” Nothing about the five mothers’ lives was the same once they brought their ventilator-dependent children home. The mothers’ sense of loss of freedom is best portrayed in these words:

I got 15 hours a week [respite care]...sure, I thought that was excellent. Before that I never went anywhere, I felt totally tied...no sense of freedom. I stayed at home 24 hours a day lookin’ after [child]...goin’ to the store was a big deal. You lose contact with all your friends ‘cause I have to live by a schedule. I couldn’t get up and go and jump and do the things that I wanted to, when I wanted to. After a while they [friends] stop asking you to go and they move on with their lives. And you can’t blame them.

Watching the clock was a constant preoccupation for the mothers, since they were tied to inflexible treatment regimes, such as enteral feedings and medication

administration. Time meant continuous deadlines. The mothers' felt that they were not free to choose what, and when, they could do something. Time was not their own and it played a key role at their place of work, at social events, and while visiting family members. Acknowledgment of how frustrating watching the clock can be is best articulated by a mother in this way:

If I'm out on nights...which is not very often I do, but if it happened that I'm at work, or if I'm called in [to work], or I may be visiting my mother or somebody...I'm watchin' the clock because I gotta be home by 10:30 at night... and I even gotta call the girls [respite workers] to get 'em to hang on, or gotta rush home, which is... frustrating you know.

Sleep deprivation, constant monitoring of equipment, isolation, and concerns about well-being were other factors that contributed to some mothers' loss of freedom. One mother described how she felt on her own and at times experienced a "great feeling of isolation," and was "resentful" about taking on all the responsibility of caring for her child when respite care workers were not present in the home. As well, the mother commented how she never liked to "put herself first," but is at a point in her life where she is unsure of how much longer she can cope with caring for her ventilator-dependent child at home. She verbalized her feelings in this way:

I took all the responsibility...I shouldn't have done that... I got resentful of all that. You know...I never like to put myself first, I never do. I always puts everything and everybody ahead of me. But after all these years...I ... just sorta got burnt out. I'm gonna need help...I need help now...even if ...in four years time... when [child] is [age of child] they could give me 24 hour care in my home where [husband] and I could come and go as we please or...provide an apartment for this child...provide the home care.

For the mothers in this study, a full night's sleep, or even several hours of uninterrupted sleep, was not something that they could look forward too, or could count on, because their sleep was always broken. The mothers had to check frequently on their child, respond to equipment alarms, and get up in the night to do procedures such as suctioning. One mother conveyed the stress and anxiety around lack of sleep in this way:

For me, I sleep very lightly and hear every different noise that the machine makes and I'm up all the time checkin' ...if [child's] ok. The stress physically and mentally of trying to keep up with a strenuous routine day-to-day tires me very easily...not having proper sleep at night...it's hard...really hard. [participant crying]

Similarly, another mother stated:

It's like I'm always on call...like you're always ready, you know, you gotta be ready to hear and get up.

The mothers' loss of freedom was further highlighted when they related how they have to wait for their respite workers to come to their homes before they can participate in any outside activity, such as attending a community function, or simply mowing the grass. Some of the mothers "banked" their hours if they knew of a special upcoming event that they would like to attend, or merely, if they planned to spend time with their partner. Despite banking their hours to give them some free time, some of the mothers felt frustrated that they constantly had to "check the time" in order to be home at a certain time to relieve the respite worker. The frustration of trying to beat the clock was at times overwhelming, and at times some of the mothers felt the desire to run away from it all.

The following remarks capture the feelings of most mothers in that regard:

I could never turn around and go because I wanted...it always had to be planned in advance....scheduled around [child]. Sometimes I bank my hours...I stay home more so I can go

somewhere every now and then...doesn't happen often, but still. Even at that, I have to leave early, say around 12:00 [midnight] 'cause the worker has to go...I am very restricted in a lot of ways. Let's see... there's times I just like to get in the truck and go in the opposite direction. [participant crying]

Many of the mothers had not taken a vacation since their child had come home from hospital because they did not feel free to do so. While mothers acknowledged that they would like to take vacations or, simply go away for the weekend, they knew that it was impossible because too few support workers were available to provide respite care. One mother's comments were typical:

It's hard to get anyone. We're trying to get someone...just to get out, or just go somewhere overnight. But anyone who comes to look after [child] thinks the work is too much with all the equipment and everything and they don't stay. We told them we'd train 'em...but they...thought it was too much for them in terms of care.

The freedom to choose to take a vacation was compounded by the guilt associated with leaving their child, and thus caused some mothers to put family vacations on hold. A few mothers indicated that they could leave their child with a family member who was qualified to do the required care, but as one mother stated: "But there's so much guilt involved when you have a sick child...you just can't do it...I can't." Other mothers shared similar feelings when they revealed that the guilt associated with leaving their child took several years for her to feel comfortable with going on a vacation with the family. One mother who described what it was like to leave her child at a pediatric hospital for respite while she and her husband and other child took a vacation also experienced guilt. She stated:

I hates leavin' [child] there [hospital] and feels guilty, but it's really

the only break we gets all year without anyone in the house.

Loss of freedom was further amplified through the presence of respite care providers in their home. The mothers were not free to do what they desired in their own home. For example, if they wanted to lounge around the house in their pajamas for the morning, they couldn't because respite care workers were present in the home. While the mothers valued the contributions of the respite care providers in the day-to-day care of their ventilator-dependent child, they also felt a great invasion of their privacy. Most of the mothers lived in rural small town areas where privacy can be a challenge at the best of times. A mother who lived in a small community commented that she can never do what she would like to do in her own home for fear of "people talkin' about what's goin' on at my house." She acknowledged that while "you have no privacy" and you are not "free" to do what you want with workers in the home, she "had really good workers." The numbers of hours of respite care for each child varied from 12 hours-135 hours per week. While the mothers knew they had to collaborate with the respite care workers as a team, their feelings about the workers were both negative and positive. One mother expressed this about one of her workers:

There's one that's been with me 10 years, she's been a godsend. Thank God there is paid help, because if there wasn't ...I wouldn't have been able to bring[child] home... 'cause I wouldn't have the support...it's challenging...it's hard. If[child] didn't have workers, ...[child] wouldn't see anybody. There's people I'm very, very comfortable with.

However, some mothers felt that dealing with respite workers could be extremely stressful. The invasion of their privacy was a great concern. The mothers were concerned

about their workers discussing their personal affairs outside of their home. One mother voiced her concern in this way:

Some workers, it worked out well, others it didn't. Some workers that I've had to deal with, [I] put them in their place. I've had workers that, you know...there was talk that went outside the home... And the privacy... I guess I'm frustrated too 'cause...a normal household where kids are growing up, there's times you gotta...put things in place. Things happen between husband and wife. I think there's times we're so stressed out that if we wanted to yell at each other, we didn't really care who was listening. It hasn't been easy.

Equally important, another mother mentioned that while you don't have the same freedom with someone coming into your house, she did not mind having respite care workers in her home "as long as [child] is being taken care of." This ambivalent attitude to the workers was constantly negotiated and re-negotiated in the mother's mind, with reality forcing them to realize that the workers were indispensable.

Although the presence of respite care workers in the home posed additional challenges and stresses, all of the mothers could readily identify the benefits of their presence. Without the respite care workers, they would be unable to care for their child at home.

Forgotten Mothers of Forgotten Children

A theme integral to the mother's experience of caring for their ventilator-dependent children was the feeling of being forgotten once they were discharged home. All of the mothers in this study acknowledged that there was limited help available in assisting them to care for their ventilator-dependent child at home, and all mothers felt

that this was an area that needed to be “looked at.” Given the complex skills that were required from the mothers to care for their ventilator-dependent children at home, the absence of further follow-up from health care professionals once they were discharged from hospital, led to feelings of being forgotten. The mothers initially felt somewhat intimidated in providing the required care, and even when they became proficient with manipulating the equipment and performing the tasks required of them (e.g., changing tracheostomies, administering medications, caring for and administering feedings through nasogastric, gastrostomy, and jejunostomy tubes), they often felt that they had been set adrift. As complicated as the technical aspects of caring for the child were, the inevitable emotional drain of feeling forgotten was especially challenging for the mothers. One mother stated:

I feels we were sent home and forgot about. That's the truth. I'm thankful for the [pediatric centre] but I only hears from them if I calls. There's no support group...no one to talk to about how I feels or anything. This is the first time...that anyone has asked me what it's like to care for [child].

While the mothers praised the medical and nursing staff at a local pediatric centre in preparing them for discharge with their ventilator-dependent children, they still reported feeling forgotten when they went home. The lack of transitional or intermediary support, along with no long-term support, proved to be very stressful for the mothers. For example, one mother indicated that when her child was being prepared for discharge after two years of hospitalization, a physician had informed her that respite services would be provided at a hospital within close proximity to her community. The mother felt that this was “a plus...because with the staff trained there, perhaps, every three or four months,

we could bring [child] there for respite.” However, when she tried to access services at the local hospital she met considerable resistance; the hospital personnel would only allow the child to stay for a weekend as opposed to a week, as requested by the mother. The mother was frustrated with the resistance and could not understand why a hospital with trained professionals could not provide assistance in the form of respite care, when she as a mother with limited training in health care was expected to care for her child at home on a permanent basis. When asked how this made her feel, the mother stated:

Very disgusted. The way we look at it, we can't understand why nurses at [local hospital] can't look after [child] when ...we had to train to look after [child] at home, but on top of that they get to have further training. They're doctors and nurses and I think they should be able to look after [child] if we can. So...my question is, why can't they look after [child]? If [child] is sent to [pediatric centre] ...that was thousands of dollars a day to keep [child] in a Pediatric Intensive Care Unit when [child] could be cared for closer to home.

The feeling of being forgotten was further illustrated by a mother who expressed that for the first two years of providing care at home to her ventilator-dependent child she had no idea about respite care services that could be available to her; so she took on the responsibility for all of her child's care. The highly skilled intensive care that was required for her child meant that the mother slept very little and therefore, left her feeling physically and mentally exhausted. She shared these feelings:

With the help and patience from the staff at the [hospital], I felt... confident to take care of my child in the manner needed. The other side of that is wondering if I would have the help I needed outside the hospital...once I got home. I never slept practically for the first two years [child] was home. I did all the care. It was hard.

The presence of close friends, family members, or partners helped to mitigate the feeling of being forgotten by the health care community. When asked who or what provided the greatest support, most of the mothers responded that their spouse, family and/or partner were their strongest supporters. However, one mother indicated how she had nobody to talk to including her partner because he never understood her feelings. This lack of immediate support intensified her feelings of being forgotten. She explained that keeping a diary had provided a partial outlet for her emotions. She stated:

I keeps a diary...I have wrote in it every day since [child] was born. I had to...I couldn't talk to [name of partner]. He never understood me. I had no one else to talk to...so I kept a diary.

In general, the mothers characterized their interactions with the health care system as adversarial. They did not view the health care system as being family-centered or helpful with their needs. The mothers identified a lack of coordination and shortage of staff as making it difficult for them to access needed support services, or even to determine what resources were available to them to aid in caring for their ventilator-dependent children. The inability to tap into existing resources further strengthened the feeling of being forgotten. One mother indicated that she has been advocating on behalf of her child for the past three years to determine what was available in terms of extra respite services and community activities in which her child could participate as an employee or as a volunteer. This mother was thoroughly frustrated in her attempts. She stated that health care workers such as physicians, nurses, and social workers were aware of her situation but as noted by the mother, “there’s never been any support” offered by health care professionals to help mothers determine what resources are available, and if,

in fact there are any. What frustrated her most was that the awareness on the part of professionals never translated into active support or assistance; this chasm increased the mother's sense of helplessness and of being forgotten. The mother summarized the feelings expressed by other mothers in this way:

Three years ago I started this...looking at what's out there [community services]. I've expressed this concern with the social worker in my area and the [pediatric centre] social worker. I have been questioning Human Resources. They know our situation. I can't say that there's been any great support. I find it very frustrating 'cause it's like I'm in this alone.

The mothers further emphasized the feeling of being forgotten as they expressed their concerns regarding the limited amount of respite care available to them. While some of the mothers were satisfied with the number of hours that they received, others desired increased hours. Given the small number of children within the province of Newfoundland and Labrador requiring mechanical ventilation, and the relatively insignificant amount of money required to pay respite workers (they receive minimum wage), the mothers wondered why the government limited the hours to the degree that they did. This frustration was intensified by a seeming shortage of suitable respite care workers. While one mother had been given extra respite care hours that she desired, she was unsuccessful in hiring anyone to fill the extra hours per month that had been provided. She stated that "we got more hours but can't get anyone to work." Another mother voiced similar concerns. She was both stressed and fearful of what the future entailed in terms of hiring suitable respite care workers:

This is why I sorta wanted to get something set up when the time comes, because...I know one of these days, it's only a matter

of time and I'm not gonna get workers. I'm not gonna get anybody to drive into this community...for, \$7.15 an hour. And the two I got now...I was very, very lucky because they just couldn't find anything to do at the time, and they told me it's only a matter of time, if they get something to do in their own community...where does that leave me? Constantly stressed. This past two or three years...I've been changing workers like day and night.

The mothers were quick to point out that by caring for the child at home, they were saving the government considerable expenses. This fear and stress about the future worked to increase the mother's sense of desertion.

The rural nature of the communities in which four of the mothers lived contributed to feelings of being forgotten. One mother living in a rural community observed that there were no resources within her community that she could avail of if she needed assistance. She noted that she could not depend on the local hospital to assist her if she needed help and stated that "there's no support groups of any kind here...you're totally on your own." The only community resource available to the mothers was the community health nurse. However, the mothers were quick to note that these nurses visited their ventilator-dependent children only if the mothers requested their services. While one mother noted that the community health nurse periodically checked oxygen saturations, [the] child's temperature, and gave the flu shot, she also noted that the community health nurse "don't do anything with [child's] equipment or anything." Yet, another mother noted that while the public health nurse would come in to see how her child was doing she was more interested in "if I had too many supplies than anything." It would appear that even if the nurse was available, the type of help that the nurse provided did not meet the needs of the mother.

The experience of being forgotten was reiterated by a mother who gave an account of how she has been lobbying with social services and other organizations over the past couple of years to obtain a wheelchair lift for her child. Despite her efforts of letter writing and telephone calls, her child is totally housebound for all winter because [child] does not have access to a wheelchair lift whereby the [child] can get outside during the winter season. The mother's simple request of wanting her child to get out at "Christmas time to see all the [Christmas] lights" epitomized the isolation and aloneness that some of these mothers struggle with on a daily basis.

According to the mothers, they would feel more included and less forgotten if some small and relatively inexpensive steps were taken to help them. The mothers identified a need to have moral and personal support from medical and nursing staff and would have been pleased with a mere telephone conversation. For example, each of the mothers indicated that they would have been pleased and consoled by a periodic telephone call from the local pediatric hospital, as had been promised to them. All of the mothers indicated that they were informed upon their children's discharge from the pediatric centre that someone would be telephoning and keeping in touch. However, as stated by one mother: "I've never, ever seen it after, I don't know what happened to it. I know there was talk of it." Furthermore, the mothers indicated that it would make things much easier if someone was calling them, instead of every time something was wrong they had to call the pediatric centre. When asked if there was anything that she would like to see in terms of resources to help her in providing care to her ventilator-dependent child, one mother expressed a sentiment that echoed the feelings of the other mothers:

I'd love to see where there's some type of contact with people... if there was just someone...who would call and let you know that they are thinking about [child] from the hospital ...and see if you're okay, and is there anything you need. Just to know that...know you're there...sometimes that helps, just to chat...like "How is [child] doing?" And, you know, just that you remember and...that [child] is not forgotten.

In addition, some of the mothers acknowledged that they would like to see programs implemented whereby their children could participate in activities outside of the home. Although the children had physical disabilities, most of the mothers viewed their children as generally intellectually and emotionally "normal." Having searched for after school programs for her child, one mother was surprised to learn that the only resources available were better suited for those who were adults with mental disabilities. She stated:

I called around looking for a place where [child] could go for activities but there's nowhere. The places I called were all for people who had mental and other disabilities...and they were for adults. Anyway, it wasn't the place for [child] 'cause...[child] is a normal child. It would be nice to have a place where [child] could go...for some fun things...like crafts or art...somewhere else to go besides school and home.

The need for a stronger liaison with healthcare providers was strongly identified by all of the mothers as a means of alleviating the feeling of being forgotten as they cared for their ventilator-dependent children at home. For some mothers the future seemed bleak without the provision of resources to help them sustain a functioning family.

Thinking About the Future

The mothers all looked to the future with concern as they wondered what it held for them personally, for their families, and most of all for their ventilator-dependent

children. In envisioning the future, mothers marveled about how their ventilator-dependent children had survived beyond their life expectancy and wondered what, if any, resources were available as they prepared for the future. Several of the mothers willingly talked about the future in anticipation of resources being put in place to enable the children to function in society in a manner as “normal” as possible. Yet, one mother could not talk about the future, while another looked to the future with sorrow. The mothers who tried to envision what the future held in store for them, described how their children would like to move out into the community to establish a sense of independence, have their own privacy, and perhaps find a job or do volunteer work. However, the mothers acknowledged that 24-hour care would be required in order for that to happen. In addition, the mothers described how their children had developed as well as any child could with their medical condition. The mothers felt frustrated as they tried to plan for the future of their children and kept being stymied in their attempts to find community resources or supports. Even when they did locate likely resources such as social workers, the Department of Health officials, physicians, nurses, and Human Resources workers, none of their contacts were of much help, thus enhancing their feelings of being forgotten and totally alone in their care-giving roles. Consequently, the mothers experienced ambivalent feelings about their child’s future. For one mother, imagining her child confined to a room for the rest of her life was more than she could deal with. In an anguished voice she stated:

There’s nothing right now...I mean...what’s out there, what there is to offer, there’s nothing. And...to think that [child] has to stay confined...in a bedroom for the rest of [child’s] life looking at the four walls...[child’s] not gonna be very happy.

I'm not gonna be able to cope with it. We're such a small voice, I don't know if we're gonna be heard...I don't know if anything is gonna be done for us.

Another mother noted that although she herself would welcome privacy, she also felt that her child would like to have privacy as well, and have the responsibility of being out on her/his own. The mother suggested that the child's longing for a sense of independence stemmed from the fact that several of the child's high school friends have moved on to post secondary education. The mother stated:

Kids [that] age, now, are gone to...University, away from their parents and I think [child] would like to have that responsibility too. I mean, [child] is normal. [Child's] almost as normal as can be only that [child's] paralyzed and on a ventilator, otherwise [child's] normal. There's lots of work that needs to be done with children like [child]. I'm sure years ago doctors never thought these children would live this long...but they have and not much has been done for them.

In contrast, other mothers lived in the shadow of death and displayed a great sense of sorrow as they projected what the future might hold for them and their children. For example, due to the severity of her child's medical condition, one mother felt that the child would not survive beyond the teenage years. Yet, every milestone that her child had accomplished encouraged the mother. For instance, in the beginning, the child was not expected to survive. However, with multiple surgeries and technological devices, the child has surpassed the odds. The accomplishments of reaching an eighth birthday, going to school, and preparing for the activities that other children experience were major feats for this child. Conversely, the agony of each hospitalization and "the torture" that the child has to endure to get through a respiratory illness has forced the mother to be realistic about the future. In reflecting on the [child's] future, the mother acknowledged

that [child's] condition was never "gonna change, and [child's] never gonna get better."

Furthermore, she acknowledged that children with this particular medical condition had not survived beyond 10 years of age. The agony of waiting to see if her child would exceed this age was excruciatingly painful. She framed her thoughts in this way:

*You know...[child's] going on eight, next year, nine...and will [the child] make it past that record of 10...and...when you're having your really bad days, you just...want the Lord to either take [child] when [child's] sick the next time...or don't take [child] at all. Like, don't take [child] when [child's] 10, don't you dare take [child] in two years...and let me suffer this out for the next two years and let [child] be tortured for the next two years, and then take [child]. And then...at times, you just wish, when [child's] sick, like, God...I'd wish it would stop.
[participant near tears]*

This mother also looked to the future in anticipation of peace, as she spoke realistically about how the day will come and "it's all gonna stop." She stated:

But you have to be aware of that day that it comes, like it's all gonna stop...[child's] been my whole life, and [child] will always be my life, no matter what. But when [child's] gone, I'll feel peace for me and [child], than more sorrow. I'm sure sorrow for a long time, but peace'll always be there once this is all over. [participant crying]

Similarly, another mother communicated that in thinking about the future she too lived in the shadow of death. While she acknowledged that she was grateful that her child was seldom hospitalized, she never knew if her child would come back home following a period of hospitalization. She noted through tears that death was frequently on her mind because of her child's medical condition. Despite these fears, the mother was quick to point out that she would not change anything about bringing her child home. Her greatest

desire for the future was to see the implementation of much needed resources to help herself and others in her situation.

Not all mothers dared to think about the future. For instance, one mother found it too difficult. By devoting herself entirely to her child, the mother had disconnected herself from her career, social events, and friends, and therefore tried not to think about the future, but rather, dealt with matters on a day-to-day basis. Despite her attempts to deny what the future entailed for her and her family, the mother admitted that the future preoccupied her at times, especially at night when she went to bed. In her struggle to cope, she tried:

*to deal day-to-day. I don't look to tomorrow. I try,
but I can't. I get up every morning, and if [child's]
well and happy, then I'm well and happy, and...that's
how I cope with it...you don't think about it all the time,
believe me, you don't 'cause you would go mad.*

Certainly, as the mothers tried to envision their future they cited concerns about their own physical and mental health. The women learned to use the technology but the lifting and care associated with the child became more difficult as the child became older. Almost all of the mothers acknowledged the increasing physical limitations of their age. The mothers were attentive to the fact that they were getting older and were concerned about who would care for their children should something happen to them. One mother expressed the feelings of all of the mothers in saying that she had provided the best care possible for her child at home, and took pride in being complimented by health care workers on how well she had accomplished that role. However, like the other mothers she feared what the future held in store for her and her child. Knowing where her child would

be and who would care for [child] in the future would create a sense of peace for the mother. The intensity of her fear comes out strongly in these words:

I'm looking ahead to the future...not just looking for a place to place [child]...I'm looking for a future for [child]. I'm not going to be here forever...we're getting up in age now...I've cared for [child] for so long and so well, that there should be something in place...really, if anything happened to me tomorrow...my God, I'd die at the thought of what would happen to the child. If I knew that [child] would have a secure place, and you know good care...at least I would have peace of mind.

In looking to the future the mothers noted that there was no incentive to save for retirement because the more money they attempted to save, the less insurance groups and government were willing to reimburse them for equipment, supplies and medications that were necessary to maintain their ventilator-dependent children at home. In contrast, when the child was hospitalized, they needed the same equipment and supplies yet the mothers never had to reveal any personal information about their financial situation; cost to the mothers was never a factor. A mother declared her frustration in this manner:

...every six months I've gotta give them [insurance representative] every private part of my life...if I was in hospital, [child] needs that same equipment and I haven't gotta, you know, tell them everything. But, because I got [child] home... every six months they have to know every bill I pay, every cent, you know...and that really irritates me because...they're not allowing any money if you want to take a vacation, and they're not allowing any money for savings...you have to go the bare necessities.

In terms of saving for the future, the mothers did not see any great benefit in doing so. As a matter of fact, the mothers were less inclined to save for the future and to spend their money paying their mortgage. One mother's encounter with a local hospital verified what other women had experienced. Upon returning to a local hospital to pick her child up

after a brief respite period at the institution, the mother was confronted by a social worker who informed her that the amount of money provided for services such as medical supplies was going to be cut due to an increase in her spouse's income. The mother expressed anger over this cut in service and promptly told the social worker that they [the hospital] would have to care for the child, as she could no longer care for [child] at home.

The mother described her experience with cost cuts in this way:

Two summer ago, social services told me they were cuttin' our money because [husband] was makin' enough money. They told us that when we came to pick [child] up after respite at [name of hospital]. I told them they would have to keep [child] there because I wasn't takin' [child] home anymore if they cut money for supplies. I'm sure they never expected me to do something like that. If we makes more money, the government takes it. What makes me mad...if [child] had to stay in hospital, it costs thousands of dollars a day. I'm doing the best I can to look after [child], and if I makes a bit extra, they [Government] cuts something. It's always a battle with supplies and equipment. I have to account for everything and it takes up so much time.

Although the mothers in this study continued to experience resentment toward government policy, and to be uncertain about the future, they maintained that keeping a positive attitude was critical to their state of well-being. In particular, they accepted the circumstances of their lives that could not be changed and made the best of those that could. The following quotation reflects one mother's resignation: "I know we gotta sacrifice as parents... those kids are born to us...it's our problem, right? But...it's a sad system out there that we don't have some extra help...we're going to need it." Similarly, another mother admitted that:

You will get depressed...but, myself and [husband] try to stay positive...if you're depressed all the time, [child] is going to

know you're depressed...I think if I was going around crying all day long, what would that do to [child], or to my marriage ...you find a way to cope with it.

CHAPTER 5

DISCUSSION

Although each of the five mothers caring for a ventilator-dependent child at home had a unique experience, they also had a number of experiences in common. In reflecting on the responses from the mothers who participated in this study, I have come to understand that they felt a great need to tell about their experiences, to connect with someone outside the family unit. Their homes are active for practically 24 hours a day, due to medication and care schedules, and the need for constant supervision of their children. Despite their busy schedules, five mothers agreed to talk with me about their experiences. Throughout the interviews the mothers shared laughter, tears, confidences, frustrations, and pride. Not one of them had ever been asked, "What is it like for you to care for your ventilated-dependent child at home, day after day, year after year?" This is remarkable since some of these children have been living at home for as long as 20 years. My study illustrates some of the consequences of technology, both positive and negative, on the lives of these caregivers. The technology associated with mechanical ventilation enabled children dependent on this technology to be cared for in their own homes and within their families. Maintaining a child on a ventilator within a home is a huge responsibility, so huge in fact that if the child were in an acute care institution, he or she would be cared for in an intensive care or special care unit. Yet, when at home, the responsibility of care most frequently falls to the mother, who is expected to take the full care of the ventilator-dependent child. The findings from this study, therefore, contribute to our knowledge and understanding of these mothers' experiences and how they are

affected in the long term by caring for a ventilator-dependent child in the home. There is perhaps no other situation where a mother has such an intense 24-hour responsibility.

Although the mothers I interviewed were proud of the care they provided to their children, their experience can best be described as one of perseverance and determination in the face of great adversity.

One of the main themes that emerged in this study was the mothers' increasing ability, and eventual competence, to take charge or be responsible for the child and family's care. Often this resulted in excellent care and advocacy for the child's needs, even at the expense of the mother's own future and well-being. A second finding is that the mother often spent more time in being a full-time nurse and caregiver than in being a parent to the child, since the child's physical care needs were so great. She was usually totally absorbed in caring for the child's nursing and medical needs, as well as overseeing the care provided by respite workers. Although continuously busy and committed to the child's needs, the mother was aware that she was experiencing a loss of personal freedom to pursue her own interests and relationships. The study also revealed that the mothers often felt that they were alone in their struggle and that once the child came home from the hospital, they and the child were forgotten. A final key finding was the realistic perspective that the mothers had about what the future held for them and their ventilator-dependent children.

This chapter is a discussion of the five themes in relation to the literature. In addition to discussing each theme and how it relates to existing knowledge on the topic, new insights are presented into further highlighting the mothers' experience of caring for

their ventilator-dependent children at home. The themes formed the core of the lived experiences of mothers as they cared for their ventilator-dependent children on a daily basis. Since each theme is connected, removing any one theme would change the understanding of that lived experience.

Taking Charge

The theme *taking charge* illustrates the complexity of these mothers' caregiving roles. Not only did these women have to move from a position of unknowing to one of knowledge, competence, and leadership, they had to learn to become advocates for their children, negotiate the medical system, and oversee the respite care that the child received. *Taking charge* involved overseeing the well-being of all family members, not only the ventilator-dependent child. The mothers' commitment to home care for their children was unwavering and involved many personal challenges, including an ever increasing sense of being on their own. The women in my study identified a number of factors contributing to their ability to cope: having a positive attitude, maintaining support systems such as family and respite care workers who were members of their local community, and advocating for the best interest of the child.

On the specific theme of *taking charge* there are similarities to findings in other studies. In Wilson et al.'s (1998) study, for example, the mothers' employed considerable internal resources in order to manage their children's situation. Like the mothers in my study, these mothers faced innumerable challenges such as adjusting to the struggle, reframing time, making sense of realities, facilitating family life, expanding caregiving,

and refusing to give up. Yet, in order to cope, they developed mastery of the situation. Similarly, the mothers who participated in a study by Valkenier et al. (2002), viewed the theme *taking charge* as essential in helping them to stay positive as they cared for their technology-dependent children on a daily basis. The strategies used by the mothers in Valkenier et al.'s study included: learning the rules of a nursing respite program, taking things one day at a time, acquiring control, staying positive, getting on with it, and searching for social support.

The theme of being able to *take charge* also supports the findings of Scharer and Dixon (1989), who explored the management style of 10 families who cared for children who were ventilator-dependent. Similar to the women I interviewed, the women who participated in their study used resources such as significant others, health care personnel, sources of financial assistance, and systems such as schools, hospitals and home care agencies. They managed their situation by maintaining support systems and advocating for the best interest of the child. In comparison, the participants in Scharer and Dixon's study had more resources to avail of than the women who participated in my study. While my work strengthens these studies' findings about the need to *take charge* and to effectively manage the situation, it provided a deeper insight into the lived experience of those mothers as they articulated how they became managers of their children's day-to-day care activities, thus enabling them with the ability to *take charge*. For example, the mothers' ability to move from having fears about managing complex technology, to mastering the intensive skills required to care for their children; from hesitating initially, to feeling confident about questioning health care professionals; from feeling

incompetent to knowing they were the best advocates for their children. In many ways the phenomenological nature of the research method facilitated achievement of this understanding of the mothers' experiences. Over time and with years of experience and perseverance, they felt that they had become stronger individuals for all that they had to endure.

In allowing the mothers to tell about their experiences at length and with a minimum of interference from the interviewer, I provided them with the opportunity to reflect on their experiences and to create meaning (van Manen, 1990) within the interview. As a result, this study yielded rich information on the progression of stages and changes in the mothers' ability to *take charge* of the care of their ventilator-dependent children. However, the positive feelings expressed by the mothers cannot be interpreted as a lack of awareness of the effects of caring for their ventilator-dependent children. On the contrary, their articulation of feelings of being forgotten, losing freedom, and being socially isolated make explicit their full awareness of the consequences of their caregiving without adequate resources.

“Full-Time Nurse, Part-Time Mom”

The second theme identified was “*full-time nurse, part-time mom*,” a caption that reflects the conflicted nature of the mothers' identity in parenting, negotiating family demands, and functioning as a nurse for her ventilator-dependent child. This theme related also to the mothers' training in caring for the child's medical and nursing needs. The data revealed that the mothers needed to learn complex nursing procedures such as

the care of mechanical ventilation, oxygen therapy, gastrostomy tubes, nasogastric tubes, enteral nutrition, tracheostomies, medications, and the physical care such as bathing. Whereas mothers with well children have the everyday concerns of caring for a child these mothers had intense fears about the new career they had never anticipated---nursing. These dual roles of nursing and parenting often meant the mothers' loss of their own dreams and freedoms, disconnection from friends, and intense loneliness. My study supports the findings of earlier studies such as those by Andrews and Nielson (1988), for instance, that show that the nursing demands on the mother are considerable and cause disruption for the entire family unit. Researchers such as Anderson and Elfert (1989), and Sims et al. (1992) have also found that restrictions on the activities of the primary caregiver, usually the mother, are prevalent among families with children dependent on technology. My study reinforces the existence of such restrictions and has the added advantage of focusing specifically on mothers of ventilator-dependent children, not just family members of technology-dependent children.

The mothers in my study experienced considerable stress as a result of the competing demands of being a "*full-time nurse and a part-time mom.*" Because their children have intense nursing and medical needs, more than most other chronically ill children, their care requires 24-hour commitment and involves a number of respite workers as well as family and friends. Likewise, at least six researchers discuss how stress from caring for a technology-dependent child at home impacts on the family socially, financially, physically, and emotionally (Leonard et al., 1993; Patterson et al., 1994; Patterson et al., 1992; Scharer & Dixon, 1989; Wegener & Aday, 1989; Youngblut

et al., 1994). Since my study focuses on mothers of ventilator-dependent children, who have more complex care needs than technology-dependent children generally, it validates that the stress on the mother in particular is great and that it has intense effects on all involved.

Loss of Personal Freedom

The theme *loss of personal freedom* points to the incredible constraints experienced by each mother interviewed. Each spoke unconditionally about the limitations of what they could do, what kinds of plans they could and couldn't make, and how they lived their lives. This demonstrated perceived loss of freedom was as difficult to cope with as the incredible physical demands of caring for the child. Loss of freedom was related to the mothers being tied to the child's stringent care schedule and to their constant need, psychological and otherwise, to be totally responsible for the child, to oversee their care, to check on the child in the night, and to ensure that the child received the best respite and personal care possible. Given the enormity of these tasks, the mothers had little or no time for personal relationships, activities outside the home, or opportunities to undertake paid employment. The mothers who provided home care for several years were the most vulnerable to isolation and as time went by these mothers took fewer breaks away from their children.

The mothers who participated in this study are home workers as well as moms; they are unpaid, unrecognized by the larger community for the valuable care they provide, and are susceptible to emotional and physical problems. Similar to other studies

(Anderson & Elfert, 1989; Gravelle, 1997; Valkenier, 2002; Wilson et al., 1998), the mothers in my study chose to assume the primary caregiving role for their children in addition to their role as a wife and mother. While other family members were trained to care for these children at home, some of the mothers took on all of the responsibility of care and refused to leave their child with anyone else. The mothers felt it was their responsibility to carry the burden of caregiving and assume the obligation of caring for their children. As well, they were not aware of other options such as placing their child in foster care, for example. Hazlett (1989), acknowledged that families need to be willing and able to undertake the responsibility of caring for technology-dependent children at home. Furthermore, Hazlett noted that health care professionals, specifically nurses, need to be aware that taking a ventilator-dependent child home may not be the best option for all families.

The question that arises then is: Is it a societal expectation that mothers assume the caregiving role of their children requiring complex technology? If so, should health care professionals take this into consideration when talking about family-based care? If health care professionals, specifically nurses, know that women assume the primary caregiving role of their ventilator-dependent children, they need to take this into account when preparing these children for discharge. If, in fact, they follow the concept of family-based care to its natural conclusion, they need to include all family members in the discharge planning. Literature confirms the burden of women as caregivers (Anderson & Elfret, 1989; Gravelle, 1997; McKeever, 1999). Those researchers noted that the sacrifices women make as caregivers often go unnoticed. Too often governments, policy

makers, and health care professionals fail to provide the necessary resources such as adequate respite care in a timely manner, resulting in mental and physical exhaustion for the caregivers.

Paradoxically, the presence of care workers in the home, which should increase the mothers' freedom, limited the freedom of the mothers who had respite care workers in their homes since they felt their privacy to be invaded and they experienced uncertainty about leaving their child with others. This forfeiture of privacy in order to have relief was similar to that described in other studies investigating the support provided by an external caregiver (Leonard et al., 1993; Patterson et al., 1994; Scharer & Dixon, 1989). The home care worker was perceived to be both an asset and a liability. Family members reported loss of freedom and of privacy, and the freedom to dress and act informally in their own home when outside workers were present.

The loss of freedom experienced by the mothers in my study resulted in feelings of isolation. Similarly, in other studies such as those by Klein-Berndt (1991) and Teague et al. (1993) isolation was part and parcel of the parent's (usually mother's) experience, given the loss of outside interests and outside contacts once the child's care became a primary factor in their lives. The impact of isolation on mothers and on others was both positive and negative. Whereas the loss of freedom and increased responsibility on the mother limited her ability to move outside the home or plan outside activities, it also resulted in her increased competence and in the strengthening of the family unit. This confirms Teague et al.'s (1993) findings of the positive and negative effects of loss of freedom. Yet, there is little doubt that the women I interviewed would have preferred

other means of strengthening their families and increasing their technological and caring competence.

Forgotten Mothers of Forgotten Children

Forgotten mothers of forgotten children refers to the mother's experience of feeling forgotten once the child was discharged home. The mothers experienced limited or no help in assisting them to care for their ventilator-dependent child when they were initially discharged to home. They felt that this was an area that needed to be addressed. Clearly, the mothers did not require much assistance from health care professionals but even the little they needed was not available. In every interview, the women pointed to the total absence of voluntary contact from the pediatric hospital once the child was discharged. A periodic telephone call to acknowledge them and their child would have been appreciated. Whether this was the case in other studies is unclear; yet, the fact that other researchers do not draw specific attention to this absence suggests that it was not as significant a factor.

Expecting families, especially mothers, to provide nursing care for their child 24 hours a day is an unrealistic expectation. Even minor increases in responsibility for the mother such as a reduced number of respite care hours can be translated into increased care burden and more importantly, into a potential increase in family disruption (Lawrence, 1994; Noyes et al., 1999). The literature notes that although endeavors have been made to provide services for children dependent on complex technology and their families, there are gaps in services that can have a tremendous effect on the ability of

families to cope, notably in the area of respite care (Robinson, Jackson, & Townsley, 2001; Valkenier, 2002). Similarly, Quint et al. (1990) indicates that the stress associated with caring for children with complex technology increases over time, especially if inadequate resources are not provided. While my research reinforces the experience of isolation described by the above researchers, the feelings of being forgotten and the lack of organized financial and nursing supports for mothers identified in my study was more pronounced. Of note was the lack of nursing services provided to the mothers. In contrast, in all of the situations described in the literature on technology and ventilator-dependent children, nursing services were provided either in the form of home care or nursing respite services. The mothers in my study had minimal nursing support and community health nurses only visited the children at the mother's request.

At times the mother's feeling of being forgotten was compounded by an adversarial relationship with health care workers; a finding in previous research (Aday & Wegener, 1989; Patterson et al., 1992; Young et al., 1994). This conflict caused stress for the mothers and intensified their feelings of being alone. My study further provides understanding of why caregivers have feelings of being forgotten and isolated. The lack of transitional or intermediary support, along with no long-term support, proved to be very stressful. For example, some of the mothers, particularly those living in rural areas could not understand why it was necessary to travel great distances to the provincial pediatric centre for respite care. Some of the mothers expressed that providing services closer to home would be a worthwhile service to them and their family members, especially their ventilator-dependent child. If respite care were available at local

hospitals, family members could visit the child frequently, which would help alleviate some of the “guilt” that the mothers experienced when they left their child at a pediatric intensive care for respite care. This is a great concern and needs to be addressed. Why is it that hospitals in rural areas in this province do not provide respite services when they have skilled professionals to care for these children? After all, the mothers in this study were expected to take on the role of “nurse” in order to care for their children at home. This further highlights the lack of service coordination upon discharge that has been outlined in the literature (Capen & Dedlow, 1998; Patterson et al., 1992; Quint et al., 1990; Youngblut et al., 1994).

An additional factor in my study was the rural and isolated nature of the mothers’ home communities, which increased the difficulty in accessing adequate professional supports or hiring competent home care workers. This factor is part of the distinctive nature of my study in relation to other studies, since it highlights the effect that geography can have on illness and care in the ventilator-dependent population. Some of the mothers acknowledged that finding suitable respite care workers was becoming problematic and thus added to their frustrations and uncertainty about the future. They felt that low wages accounted for a part of the problem as well as the fact that home care workers were afraid to take on the responsibility of caring for a child with complex technology. Support for this finding was noted in the literature (Klein-Berndt, 1991; Youngblut et al., 1994). The lack of trained home care workers to provide respite care contributed to parent’s frustrations was identified in Gravelle’s (1997) study who noted

that because of changing family needs over time, frequent family assessments are needed to prevent a crisis situation brought on by years of 24-hour care.

The feeling of being forgotten also applied to the children's sense of being isolated. Some of the mothers acknowledged that they would like to see programs implemented whereby their children could participate in activities outside of the home. This request was related to the mothers' desire to help their children experience life similar to other children their own age. However, it was a concern for some of my participants, especially for those who had children reaching young adulthood and who had expressed an interest in pursuing activities such as volunteering or finding employment outside their home environment. Is this a realistic expectation? This issue did not arise in the published literature, either because access was available or because it was a non-issue for parents.

Thinking about the Future

The final theme in my study was *thinking about the future*. With the exception of one participant who found it too difficult to think about the future, the mothers had a number of concerns in relation to their child's future as well as their own. They were preoccupied with concerns about who would care for their children if they were unable to care for them. Instead of being a source of hope or inspiration, the future was sometimes unbearable to contemplate since it inevitably led to feelings of uncertainty. Yet, facing the future was an integral part of meeting their children's complex care needs. Some of the mothers tried relentlessly to see what resources their children could access, but

without success. There is an incredible emotional cost of caring for a child who is ventilator-dependent. It has been noted in other researchers' findings that the day-to-day worries and the anxiety and concern about the future takes a substantial toll on all involved (Leonard et al., 1993; O'Brien, 2001; Patterson et al., 1992; Patterson et al. 1994; Scharer & Dixon, 1989; Wegener & Aday, 1989; Youngblut et al. 1994). Given the circumstances, concerns about the quality of life and life expectancy of their child, who would care for their child in the future if their primary caregiver was no longer able, whether or not the children would have access to adequate financial resources and concerns about their own future health and well-being are reasonable worries (O'Brien).

Another aspect of this theme was the problems the mothers experienced in trying to plan for their future, given the lack of financial resources and the financial disincentives to save and plan for their future (i.e., if they earned any additional income, government would decrease any supports it provided). Although general financial concerns are cited in studies such as Andrews and Neilson (1988), Patterson et al. (1994), Teague et al. (1993), Scharer and Dixon (1989), Wegener and Aday (1989), my study highlights specific issues such as the effect of punitive government policies like clawback of supports for increased earnings. My participants' focus on this issue may reflect the fact that there is no plan or policy in this province to address the needs and concerns of these mothers and their children. Consequently, their incomes and well-being are negatively affected by the financial costs of caring for their ventilator-dependent children.

As they reflected on the future, several of the mothers made reference to the fact that their children had surpassed their life expectancy. They wondered that if their life

expectancy had initially been thought to be longer, would government officials have done more in regards to providing services. The mothers attributed their child's survival to the excellent care that they received at home in the presence of family and friends. There is evidence in the literature to support the assertion that technology-dependent children who have a caring family and are living at home have better psychological outcomes (Hamlett et al., 1994; O'Brien, 2001). Furthermore, in her study that explored family experiences with long-term childhood technology, O'Brien acknowledged that this is an area of research that is lacking and should be explored in order to give families the recognition that they deserve in contributing to the length and quality of life for their children.

Summary

In many respects, this study supported the findings of Wilson et al. (1998), which focused on the mothers' experiences of caring for their ventilator-dependent children, and which revealed the maternal process skills such as hoping, caring, problem-solving, as well as strategies such as adjusting to the struggle and reframing time. Like Wilson et al.'s study, I also focused directly on mothers caring for ventilator-dependent children and their experiences of both parenting and nursing the child. My study substantiated the huge social, financial, physical, and emotional costs of caring. Using a phenomenological approach, my research yielded rich data about how the mothers coped and lived in a situation without adequate resources, geographic isolation, and lack of contact with other mothers and children in a similar situation. In addition, my study provided insight into the experience of facing the future, coping with a non-responsive and at times punitive

financial system, and negotiating a complex medical illness and medical system. Having the mother's express their experiences emphasized the challenge that they undertook when they brought their child home from an intensive care environment. Invariably, the mothers rose above the challenge to exemplify best practice of how to provide an intensive level of care with much love and dignity. As the mothers evoked years of memories they helped me to better understand why they diligently care for their children in the way that they do. As noted by Cavanagh (1999), their stories confirm that each of them provided extraordinary care to enable their children who, during hospitalization and *connected* to life support became *disconnected* from their childhood, but once they were discharged to home they became *reconnected* to childhood despite being *dependent* on mechanical ventilation.

CHAPTER 6

NURSING IMPLICATIONS AND SUMMARY

This research explored the lived experience of five mothers who care for their ventilator-dependent children at home. The findings of the study have been compared to existing studies to show how they confirm and challenge existing research. The intricacy of caring for the ventilator-dependent population of children has been explicated in the preceding pages, with a view to demonstrating how these mothers live, think, and feel about their experience. This chapter discusses implications for the nursing profession, and provides a summary of the study.

Nursing Implications

The findings of this study have implications for nursing practice, nursing education, and nursing research in relation to mothers caring for ventilator-dependent children at home. The findings have particular relevance for policies regarding the provision of additional supports to the mothers of these children. In addition, the findings may increase the knowledge base of nurses who have the potential to be key resources in the coordination of services, once the child is discharged from hospital.

Nursing practice. The results of this phenomenological study, which have highlighted the unique experiences of mothers caring for ventilator-dependent children, have implications for nursing practice in situations where care is provided to the same or a similar population of children. All of the mothers expressed the need for contact with a

professional who knew their circumstances, who could coordinate services for them, and simply acknowledge their situation by calling them at home to inquire about their child. This suggests that nurses need to focus on strategies such as contacting families with unique caregiving needs, in order to provide them with the supports they need (Wright & Leahey, 1990).

The implementation of an advanced practice nurse or home care coordinator specializing in the area of pediatrics, specifically in the area of critical care, would be an asset to this population. This begs the question whether it is realistic to provide a coordinator for the mothers and children in this study given the small population of ventilator-dependent children within the province of Newfoundland and Labrador. Based on the data analysis from this study however, I would argue that the need is clearly there and I strongly recommend that a coordinator be assigned to act as a liaison between the multiple service providers caring for ventilator-dependent children and their families at home. The careful coordination of services and vigilant follow-up of these children and their families cannot be stressed too much. To aid in justifying the role of an advanced practice nurse or home care coordinator for ventilator-dependent children and their families in this province, her/his client population could be broadened to include other groups of children who are dependent on technology (e.g., children home on oxygen therapy, children with tracheostomies, children dependent on gastrostomy tubes for nutrition). As Kaufman and Hardy-Ribakow (1987) point out, without an effective coordinator, fragmentation can easily occur when implementing even the best possible discharge plan by qualified caregivers. In addition to conducting comprehensive

assessments, the coordinator could provide counseling, psychosocial support, and family education. By effectively interacting with mothers of technology-dependent children, nurses will enhance the mother's caregiving experience (Nelson, 2002).

Although this thesis focused on mothers and not the whole family unit, there are implications for family intervention and support. This study showed that the mothers cared deeply for their children to the point of feeling guilty about leaving them, even temporarily. The mothers could perhaps benefit from a reciprocal relationship with an advanced practice nurse or home care coordinator for instance, by which each recognized the other's expertise (Wright & Leahey, 2000). If the relationship was a good "fit" the mothers might be encouraged to socialize more with their partners, or with extended family and friends outside of their home, and perhaps relinquish some of their child care duties. This could result in benefits for the entire family unit. In addition, the relationship between the nurse coordinator and the mothers could be further strengthened through the use of support programs such as telephone groups that could address the needs of mothers and their families, especially those living in rural communities. For example, the use of telephone groups have been successful for caregivers of people who have multiple sclerosis, people who have acquired immune deficiency syndrome (AIDS), and those receiving psychotherapy. Due to the demanding schedules of these mothers, a telephone support system could act as a promising intervention service as it would allow them to participate from their homes (Rounds, Galinsky, & Stevens, 1991).

No one field of practice is capable of providing all the necessary coordination and integration of services necessary for the families and children who are ventilator-

dependent. Therefore, collaboration using a multidisciplinary approach to caring for children with complex technology is warranted (Ratliffe et al., 2002). Input from all health care disciplines is needed to develop and implement a complex care plan for both the child and the family (Capen & Dedlow, 1998; Kirk, 1999). Ideally, optimizing nursing care for families of technology-dependent children should begin during the hospitalization of the child. This could involve the use of family interventions as outlined by Wright and Leahey (2000), or the development of family-centered programs that are specifically designed to meet the needs of technology-dependent children and their families (Cross, Leonard, Skay, & Rheinberger, 1998). Nursing interventions that focus on enhancing skills and learning, and discharge programs that have been developed for the care of technology-dependent children (Haas, Gray, & McConnell, 1992; Lawrence, 1994; Hill, 1993) need to be incorporated by nurses in order to make the transition from hospital to home successful.

While critical care nurses possess the skills in managing the complex medical child in a hospital environment, nurses working in the community may not possess the same skills. Consequently, relationships between nurses in the hospital environment and those in the community need to be strengthened to provide support to mothers caring for a ventilator-dependent child at home. Extending the role of the hospital's multidisciplinary team to include community health nurses, community agencies, and family members is an important part of providing quality care to children requiring complex technology (Hochstadt & Yost, 1989). Nurses caring for children with complex technology need to act as advocates, to ensure that appropriate formal and informal

supports are available to alleviate the stress and loneliness that was described by the mothers who participated in this study.

The mothers in this study noted that despite efforts to be heard, health care professionals and policy makers are not meeting their concerns. They attributed the dismissal of their concerns to the small number of ventilator-dependent children in this province. One major need is for a periodic break from the overwhelming role of caring for their child, before the stress takes too great a toll on them and the whole family unit. Since mothers valued and experienced less stress when they received in-home nursing respite services, it is imperative that nurses actively develop, support, promote, and implement healthy policy that will provide a comprehensive and family-based care for children who are ventilator-dependent (Valkenier et al., 2002). Nurses need to be politically active to ensure that the needs of mothers and the needs of these children are met. Ongoing collaboration with these mothers is necessary to support the parent-child relationship and the mother's perception of her role and expectations. To facilitate a successful transition from hospital to home, a strong support system should be implemented to cover areas such as respite and nursing services, financial resources, and community services such as support groups. If these support structures are not present, as was the case in this study, mothers and their families may be at risk for burnout.

Furthermore, nurses need to examine their own personal values and beliefs to effectively interact with mothers caring for ventilator-dependent children at home. Nurses need to be aware that they are partners with the mothers and must be sensitive to the implications in providing care to the child with complex technology. Nurses need to be

attuned to both the needs of the child and the mother as well as the impact of the family on the care challenge, and reciprocally, the impact of the care challenge on the family.

Nursing education. The findings of this study have implications for nursing education. Nursing programs, both at the undergraduate and graduate level, need to include course content that prepares nurses to manage children with complex, but stable, medical conditions, who are ventilator-dependent. The nursing curriculum should include material on how to be supportive, facilitative, and informative in dealing with mothers caring for their ventilator-dependent child.

Clinical nurse educators also have a role to play. Throughout the calendar year, they should provide seminars to staff nurses on the concepts of family-based care and home health care. As well, they need to provide research-based seminars that focus on the individual needs and concerns of mothers caring for ventilator-dependent children.

Although opportunities may be limited in this province, nurse educators should avail of opportunities whereby nursing students can care for ventilator-dependent children and their families in various settings (e.g., hospitals, clinics, and client homes). In doing so, nursing students can witness, and better understand, the impact that caring for ventilator-dependent children has on mothers and families. In addition, student nurses should be taught about the need to be sensitive to the caregiving experience of mothers raising ventilator-dependent children. Student sensitivity and awareness are enhanced when nurse educators incorporate research findings related to the subject, and avail of opportunities to discuss the findings with students in a classroom environment. The

findings of the study reported in this thesis provide insights into the experiences of maternal caregiving, as well as building a foundation for understanding effective nursing encounters with lay caregivers. Furthermore, nursing students need to be encouraged to explore with mothers and families their experiences of taking care of their ventilator-dependent children at home. This study shows how important it is to focus on the mothers, since they are integral to teaching about caregiving to both formal and informal caregivers.

Nursing research. The most comprehensive research methods cannot find out all there is to be known about a particular phenomenon. As such, future research is warranted in several areas. First of all, the literature review identified that more qualitative research needs be done on the meaning of mothers' experiences of caring for ventilator-dependent children at home. While this study will add to our limited understanding, there are considerable gaps in our knowledge, particularly with regard to how mothers of different cultural groups experience caring for ventilator-dependent children at home. Research is also needed in order to understand more fully the positive and rewarding aspects of caring for ventilator-dependent children at home. The mothers in this study were happy to have their child at home and while there are many challenges, the mothers felt it was rewarding. A study to explore the impact of these rewards is necessary to see if they have an effect on the physical and emotional well-being of the caregiver. Research on the capacity of the family to respond to the challenges of care is also necessary.

Research from a fathers' perspective on the impact of having a child dependent on mechanical ventilation was notably absent. Although some researchers (Leonard, Brust, & Patterson, 1991; O'Brien, 2001; Patterson et al., 1992) have indicated that financial, psychological, and psychosocial issues are concerns for fathers, a need exists for further studies to be conducted on the extent of these concerns and the impact that they have on fathers' engagement in care for the child and the entire family.

As well, a review of the research literature in relation to the impact of technology on siblings was remarkably absent. In my study, the mothers who had other children noted that while the entire family unit was affected by having a child dependent on a ventilator (e.g., family activities such as family vacations curtailed), overall it was difficult to ascertain the impact of having a sibling dependent on mechanical ventilation. While the mothers tried to protect the unaffected child(ren) by not having them directly involved in the daily care of their sibling, for example, they did not perceive there to be a negative effect on other siblings. In fact, one mother noted that a strong bond had formed between her child who was dependent on mechanical ventilation and a younger sibling. Two studies were located which indicated that technology within the home could have negative effects on siblings such as behavioral changes, increase in responsibility, and feelings of neglect (Clarke, 1995; Klein- Berndt, 1991). However, the findings related to siblings and technology have been described from the parents' point of view and not from the sibling's perspective, and specifically, minimal attention has been paid to how the siblings are affected on a psychosocial level (O'Brien, 2001). This is clearly an area for further exploration.

In this study, the mothers acknowledged that assuming responsibility for the technological aspects of their child's care became less difficult over time, whereas dealing with the resultant isolation and loss of freedom became increasingly difficult. A study to determine the complex interconnection of these factors would be helpful in understanding the mothers' experience, and especially in understanding how mothers become comfortable with complex technology, as well as how long it takes to reach an acceptable comfort level.

In addition, research on how parents of ventilator-dependent children become advocates for their children could help health care professionals become more skillful in fostering this development (Scharer & Dixon, 1989). In the absence of organized support and relevant health care policies this advocacy role is especially important, as it may increase open communication among all the stakeholders including health care professionals, government officials, and families.

Intervention studies, in particular family intervention studies, are required to determine the kinds of services and resources that caregivers need when they are discharged from hospital to home. For example, what types of services would mothers and families deem necessary to adequately meet the needs of their ventilator-dependent child and their family? What services are required for mothers and their families to enhance coping skills after the initial discharge from hospital to home?

With time and as caregivers get older and are no longer able to care for their child, who will then take on the caregiving role? Who will be responsible for the costs that are associated with caring for ventilator-dependent children if the primary caregiver

is no longer able to provide care? Is there any reason why ventilator-dependent children could not move out of their homes and try to become integral members of society by finding employment, becoming volunteers, and attending post secondary institutions if the appropriate resources were implemented? Other researchers have raised similar questions in relation to the mother caregiving experience (Valkenier et al., 2002; Wilson et al., 1998). Mothers encounter many challenges to perform the roles of both a mother and a caregiver. It should not be the mother's responsibility to be politically active (McKeever, 1999) as they already have a full schedule meeting the care demands of their children. Therefore, these studies are needed in order to determine the services that are required on a continuous basis to maintain the mothers' physical and emotional well-being.

The perspective of community health nurses, health care workers, and respite care workers who care for ventilator-dependent children in their homes and communities also need to be explored. Researching the phenomenon of mothers caring for ventilator-dependent children at home from the perspective of these professionals and non-professionals would be beneficial.

Summary

Advances in medical technology have seen an increase in the survival rates of children who have suffered through once fatal illnesses. Once the surviving child returns to her or his home, mothers provide competent and safe care, which helps to keep the child alive and comfortable. Yet, the psychosocial dimensions of caring for these

children, especially ventilator-dependent children, remain momentous for the mothers.

Therefore, it is imperative that health care providers, specifically nurses, explore the types and quality of services that are available for ventilator-dependent children and their families.

This phenomenological study, which highlighted the lived experiences of five mothers caring for their ventilator-dependent children at home, utilized van Manen's (1990) method to explore the question: What does it mean to be a mother caring for a ventilator-dependent child? From the interview data five themes were identified: (a) taking charge, (b) "full-time nurse and part-time mom," (c) loss of personal freedom, (d) forgotten mothers of forgotten children, and (e) thinking about the future.

This study has provided considerable information for health care providers to better understand the effects of technology on both mothers and their families. More importantly, it can hopefully assist nurses in planning and implementing effective and holistic care for these mothers and their families. Finally, my study provides a firm foundation and springboard for additional research on mothers caring for ventilator-dependent children at home.

REFERENCES

- Aday, L.A., & Wegener, D.H. (1988). Home care for ventilator-assisted children: Implications for the children, their families, and health policy. *Children's Health Care, 17*, 112-120.
- Aday, L. A., & Wegener, D. H. (1989). Home care for ventilator-assisted children. *Health Affairs, 8*, 137-147.
- Allen, N. L., Simone, J. A., & Wingenbach, G. F. (1994). Families with a ventilator-assisted child: Transitional issues. *Journal of Perinatology, 14*(1), 48-55.
- Anderson, J.M., & Elfert, H. (1989). Managing chronic illness in the family: Women as caretakers. *Journal of Advanced Nursing, 14*, 753-743.
- Andrews, M., & Nielson, D. (1988). Technology dependent children in the home. *Pediatric Nursing, 14*, 111-114, 151.
- Baginski, Y. (1994). Roadblocks to home care. *Caring, 13*, 18-24.
- Boyd, C.O. (1993). Philosophical foundations of qualitative research. In P. Munhall & C.O. Boyd (Eds.), *Nursing research: A qualitative perspective* (2nd ed., pp. 66-93). New York: National League for Nursing Press.
- Canadian Institute for Child Health. (2000). *The Health of Canada's Children: A CICH Profile*. Ottawa, ON.
- Cavanagh, E.E. (1999). *Maintaining a childhood: A phenomenologic study of family experiences providing home care for chronically ill, technology-dependent children*. Unpublished doctoral dissertation. University of Washington, Seattle.
- Capen, L. C., & Dedlow, E. R. (1998). Discharging ventilator-dependent children: A continuing challenge. *Journal of Pediatric Nursing, 13*, 175-184.
- Clarke, J. (1995). Rural home care of a technology-dependent infant. *Canadian Family Physician, 41*, 1051-1056.
- Cross, D., Leonard, B. J., Skay, C. L., & Rheinberger, M. M. (1998). Extended hospitalization of medically stable children dependent on technology: A focus on mutable family factors. *Issues in Comprehensive Pediatric Nursing, 21*, 63-84.
- Diehl, S., Moffitt, K., & Wade, S. (1991). Focus group interviews with parents of children with medically complex needs: An intimate look at their perceptions and feelings. *Children's Health Care, 20*, 170-178.

- Fleming, J., Challela, M., Eland, J., Hornick, R., Johnson, P., Martinson, I., Nativio, D., Nokes, K., Riddle, I., Steele, N., Sudela, D., Thomas, R., Turner, Q., Wheeler, B., & Young, A. (1994). Impact on the family of children who are technology dependent and cared for in the home. *Pediatric Nursing*, 20, 379-388.
- Gravelle, A. M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing*, 25, 738-745.
- Haas, S., Gray, H., & McConnell, B. (1992). Parent-professional partnerships in caring for children with special health care needs. *Issues in Comprehensive Pediatric Nursing*, 15, 39-53.
- Hamlett, K. W., Walker, W., Evans, A., & Weise, K. (1994). Psychological development of technology-dependent children. *Journal of Pediatric Psychology*, 19, 493-503.
- Harrigan, R. C., Ratliffe, C., Patrinos, M. E., & Tse, A. (2002). Medically fragile children: An integrative review of the literature and recommendations for future research. *Issues in Comprehensive Pediatric Nursing*, 25, 1-20.
- Hazlett, D.E. (1989). A study of pediatric home ventilator management: Medical, psychosocial, and financial aspects. *Journal of Paediatric Nursing*, 4, 284-294.
- Hill, D. S., (1993). Coordinating a multidisciplinary discharge for the technology-dependent child based on parental needs. *Issues in Comprehensive Pediatric Nursing*, 16, 229-237.
- Hill, L. V., & Thompson, M. K. (1994). Case management of technology-dependent children: A family-centered approach. *Journal of Health Care Practice*, 6, 37-41.
- Hochstadt, N. J., & Yost, D. M. (1989). The health care-child welfare partnership: Transitioning medically complex children to the community. *Children's Health Care*, 18(1), 4-11.
- Kaufman, J., & Hardy-Ribakow, D. (1987). Home-care: A model of a comprehensive approach for technology-assisted chronically ill children. *Journal of Pediatric Nursing*, 2, 244-249.
- Kirk, S. (1998). Families' experiences of caring at home for a technology-dependent child: A review of the literature. *Child: Care, Health and Development*, 24, 101-114.

- Kirk, S. (1999). Caring for children with specialized health care needs in the community: The challenges for primary care. *Health and Social Care in the Community*, 7, 350-357.
- Klein-Berndt, S. (1991). Bronchopulmonary dysplasia in the family: A longitudinal case Study. *Pediatric Nursing*, 17, 607-611.
- Lawrence, P. (1994). Home care for ventilator-dependent children: Providing a chance to live a normal life. *Dimensions of Critical Care Nursing*, 3(1), 42-52.
- Leonard, B., Brust, J.D., & Nelson R.P. (1993). Parental distress: Caring for medically fragile children at home. *Journal of Paediatric Nursing*, 8, 22-30.
- Leonard, B., Brust, J.D., & Patterson, J. (1991). Home care reimbursement for technology-dependent children: Its impact on parental distress. *Lifestyles: Family and Economic Issues*, 12(1), 63-76.
- Leonard, B. J., Brust, J. D., & Sielaff, B. H. (1991). Determinants of home care nursing hours for technology-assisted children. *Public Health Nursing*, 8, 239-244.
- McKeever, P. (1996). The family: Long-term care research and policy formulation. *Nursing Inquiry*, 3, 200-206.
- McKeever, P. (1999). Between women: Nurses and family caregivers. *Canadian Journal of Nursing Research*, 30, 185-191.
- Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage Publications.
- Murphy, K.E. (1997). Parenting a technology-assisted infant: Coping with occupational stress. *Social Work in Health Care*, 24(3/4), 113-126.
- Nelson, A. M. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research*, 12, 515-530.
- Noyes, J., Hartmann, H., Samuels, M., & Southall, D. (1999). The experiences and views of parents who care for ventilator-dependent children. *Journal of Clinical Nursing*, 8, 440-450.
- O'Brien, M. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing*, 14, 157-163.

- Office of Technology Assessment. (1987). *Technology-dependent children: Hospital vs. Homecare-A technical memorandum* (publication No. OTA-TM-H-38). Washington, DC: U.S. Government Printing Office.
- Olsen, R., & Maslin-Prothero, P. (2001). Dilemmas in the provision of own home respite support for parents of young children with complex health care needs: Evidence from an evaluation. *Journal of Advanced Nursing*, 34, 235-256.
- Patterson, J., Jernell, J., Leonard, B., & Titus, J. (1994). Caring for medically fragile children at home: The parent-professional relationship. *Journal of Pediatric Nursing*, 9, 98-106.
- Patterson, J., Leonard, B., & Titus, J. (1992). Home care for medically fragile children: Impact on family health and well-being. *Journal of Developmental and Behavioural Paediatrics*, 13, 248-255.
- Quint, R.D., Chesterman, E., Crain, L.S., Winkleby M., & Boyce, W.T. (1990). Home care for ventilator-dependent children. *American Journal of Diseases in Children*, 144, 1238-1241.
- Ratliffe, C. E., Harrigan, R. C., Haley, J., Tse, A., & Olson, T. (2002). Stress in families with medically fragile children. *Issues in Comprehensive-Pediatric Nursing*, 25, 167-188.
- Robinson, R. (1990). Ventilator dependency in the United Kingdom. *Archives of Disease in Childhood*, 65, 1235-1236.
- Robinson, C., Jackson, P., & Townsley, R. (2001). Short breaks for families caring for a disabled child with complex needs. *Child and Family Social Work*, 6, 67-75.
- Rounds, K. A., Maeda, J. G., & Stevens, L. S. (1991). Linking people with AIDS in rural communities: The telephone group. *National Association of Social Workers, Inc.*, 36(1), 13-18.
- Scharer, K., & Dixon, D.M. (1989). Managing chronic illness: Parents with a ventilator-dependent child. *Journal of Pediatric Nursing*, 4, 236-247.
- Sims, S. L., Boland, D. L., & O'Neill, C. A. (1992). Decision making in home health care. *Western Journal of Nursing Research*, 14, 186-200.
- Smith, S. J. (1991). Promoting family adaptation to the at-home care of the technology-dependent child. *Pediatric Nursing*, 14, 249-258.

- Teague, B.R., Fleming, J.W., Castle, A., Kiernan, B.S., Lobo, M.L., Riggs, S., & Wolfe, J.G. (1993). 'High-tech' home care for children with chronic health conditions: A pilot study. *Journal of Paediatric Nursing*, 8, 226-232.
- Valkenier, B. J., Hayes, V. E., & McElheran, P. J. (2002). Mother's perspective of an in-home nursing respite service: Coping and control. *Canadian Journal of Nursing Research*, 34(1), 87-109.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Wegener, D. H., & Aday, L. A. (1989). Home care ventilator-assisted children: Predicting family stress. *Pediatric Nursing*, 15, 371-376.
- Wilson, S., Morse, J.M., & Penrod, J. (1998). Absolute involvement: The experience of mothers of ventilator children. *Health and Social Care in the Community*, 6, 224-233.
- Wright, L. M., & Leahey, M. (1990). Trends in nursing of families. *Journal of Advanced Nursing*, 15, 148-154.
- Wright, L. M., & Leahey, M. (2000). *Nurses and families: A guide to family assessment and intervention*. (3rd ed.). Philadelphia: Davis.
- Youngblut, J. M., Brennan, P.F., & Sewgart, L.A. (1994). Families with medically fragile children: An exploratory study. *Paediatric Nursing*, 20, 463-468.

APPENDICES

APPENDIX A
Interview Guide

Interview Guide

The interview will be introduced by telling the participant of the researcher's interest in her thoughts, feelings, or concerns as the mother of a child who is ventilator dependent. The researcher will state: "I understand that you have a daughter/son who is ventilator dependent. I would like for you to tell me about your experience as the mother of a child who is dependent on a ventilator." The participant will be encouraged to talk about anything that will enable the researcher to understand her experience.

The following questions will be used during the interview as a guide to data collection. Prompts such as "Can you tell me more about that"? which are clarifying, but not leading, may also be used.

1. What does it mean to you to be a mother of a child who is mechanically ventilated?
2. Describe how you felt when you learned that your child would need a ventilator to live?
3. Describe your adjustment period.
4. How prepared did you feel for discharge from the Pediatric Intensive Care Unit (PICU) to home? What was the most helpful? Least helpful?
5. What was required of you to learn how to care for your child who is ventilator dependent?
6. How has having a child who is ventilator dependent affected your life? For example, what changes have you had to make?
7. What do you find most difficult about being the mother of a child who is ventilator dependent?
8. What are the positive aspects that have resulted from being the mother of a child who is ventilator dependent?
9. What have you found to be the most beneficial in helping you care for your child?
10. Whom have you found to be the most supportive in helping you care for your child?
11. Do you have respite care? If so, how many hours per day of respite care do you receive? Do you feel that this is adequate?
12. How has having respite workers impacted upon your life?

13. Are there resources within your community to help you care for your child?
14. Has having a child who is ventilator dependent changed your interactions within your family; with your child; with other children; or with your spouse?
15. Is there anything else you would like to tell me about your experience as a mother of a child who is ventilator dependent?

APPENDIX B

**Letter of Approval from the Research Proposals Approval Committee,
Healthcare Corporation of St. John's, NL**

APPENDIX C

Letter to the Intermediary

8 Duff's Cr.
Paradise, NL
A1L 2A3

Ms. Dianne Reddy
Divisional Manager, Pediatric Intensive Care
Janeway Child Health Centre
300 Prince Philip Drive
St. John's, NL
A1B 3V6

Dear Ms. Reddy:

I am asking for your assistance in conducting a nursing research study as part of the requirements for the Master of Nursing degree at Memorial University of Newfoundland. The title of the research study is: The Experiences of Mothers Caring for Ventilator Dependent Children: A Phenomenological Study.

I am hoping that you can assist me by acting as an intermediary in accessing the population of mothers whose children require mechanical ventilation. The study will involve two audiotaped interviews during which the participants will be asked to talk about their thoughts, feelings and/or concerns of being mothers of children requiring mechanical ventilation.

The Human Investigations Committee, Memorial University of Newfoundland, will review the research proposal. Permission to conduct this study will also be sought from the Health Care Corporation of St. John's.

I would appreciate it if you would identify prospective participants, make initial contact with them, and obtain from them permission for me to seek their participation in this study. Enclosed is the specific information to be given to each mother.

Thank-you for considering this request. I will contact you within one week to discuss this study further. Please do not hesitate to contact me at 777-8173(w) or 781-1724(h) if you have any concerns or questions.

Sincerely,

Denise English, RN, BN

APPENDIX D

Consent Form

Faculty of Medicine, School of Pharmacy, School of Nursing of
Memorial University of Newfoundland;
Newfoundland Cancer Treatment and Research Foundation;
Health Care Corporation, St. John's

Consent to Take Part in Health Research

TITLE: The Experiences of Mothers Caring For Ventilator Dependent Children: A Phenomenological Study

INVESTIGATOR(S): Denise English (Graduate Student, Nursing) (709 781-1724)
Dr. Shirley Solberg (777-6873)
Lorna Bennett (777- 7332)

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher(s) will:

- discuss the study with you
- answer your questions
- keep confidential any information that could identify you personally
- be available during the study to deal with problems and answer questions

If you decide not to take part or to leave the study this will not affect your health care.

1. Introduction/Background:

Over the last several years, there has been an increase in the degree of medical involvement and use of sophisticated technologies of children being discharged to home environments. There is a paucity of literature about the experience of mothers who have ventilator dependent children. This study should contribute to the body of knowledge related to mothers who have a ventilator dependent child and add new knowledge in relation to the maternal experience. As more mothers undertake and share the primary caregiving role for children, a greater understanding of their experience is essential. This study may lay the groundwork for future studies of nursing interventions to assist mothers in coping with and managing a child who is ventilator dependent.

2. Purpose of study:

The purpose of this study is to explore the lived experience of mothers caring for ventilator dependent children.

3. Description of the study procedures and tests:

During the first interview, you will be asked to talk about your thoughts, feelings and concerns as the mother of a child/children who requires mechanical ventilation. You will be

Initials: _____

asked questions which should help you to describe your experience. During the second interview you will be asked to read a written summary of major themes identified from your first interview, confirm whether the summary accurately reflects your experiences with caring for a child that requires mechanical ventilation, and provide any information that you consider important for clarifying your experiences. Both interviews will be audiotaped, with your permission. The tapes will be erased when the study is completed. At the end of the first interview, you will be asked questions concerning personal information including your age, marital status, occupation, educational level, and the age, gender and position in the family of the child/children requiring mechanical ventilation.

4. Length of time:

The study will involve two interviews. The first interview will last approximately one hour and the second interview will last approximately 45 minutes. The second interview should take place within 2 months of the first interview.

5. Possible risks and discomforts:

There are no foreseeable risks from participating in this study. It is possible that certain questions may elicit uncomfortable memories. If you find that any questions make you feel uncomfortable, you may refuse to answer them. You may terminate the interview at any time as well as your participation in the study. All information that you provide will be kept strictly confidential, secured in a locked cabinet, and accessible only to the principal investigator and thesis co-supervisors. Your name will not appear on the audiotape or written copy.

6. Benefits:

We cannot guarantee that you will benefit from taking part in this study.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. Confidentiality:

Information obtained from you or about you during this study that may be identifying will be kept confidential by the investigator. Your name will not be recorded with any of the responses to the questions, nor will it be identified in any discussion or written report of the study findings. The investigator will be available during the study should you have any concerns or questions about the study. If you have any questions regarding this study you may address them by contacting Denise English at (709) 781-1724. If you have concerns about your rights as a research participant you could address them to the Human Investigations Committee, Memorial University of Newfoundland at (709) 777-6974. Your signature on the consent form indicates that you have understood the information regarding your participation in this research project and that you agree to participate. In no way does this waive your legal rights nor release the principal investigator from her legal and professional responsibilities.

Initials: _____

Signature Page

Study title: The Experiences of Mothers Caring For Ventilator Dependent Children: A Phenomenological Study

Name of principal investigator: Denise English

To be filled out and signed by the participant:

Please check as appropriate

I have read the consent [and information sheet].	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received sufficient information about the study.	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- at any time
- without having to give a reason
- without affecting my future care

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I agree to take part in this study. Yes { } No { }

Signature of participant

Date

Signature of witness

Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Date

Telephone number: _____

Initials: _____

APPENDIX E

Letter of Approval from the Human Investigations Committee



