

INTENSIVE CARE PATIENTS' PERCEPTIONS OF THE
EXPERIENCE OF MECHANICAL VENTILATION

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DOCTOR OF PHILOSOPHY DEGREE
IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

BY

RHONDA RENAE SCHUMANN, MSN

DENTON, TEXAS

MAY 1999

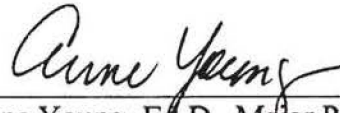
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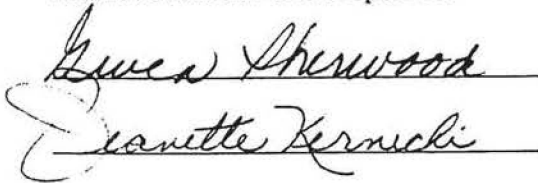
To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a dissertation written by Rhonda Renae Schumann entitled "Intensive Care Patients' Perceptions of the Experience of Mechanical Ventilation." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.

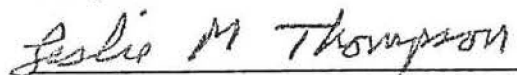


Anne Young, Ed.D., Major Professor

We have read this dissertation
and recommend its acceptance:



Accepted:



Associate Vice President for Research
and Dean of the Graduate School

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DEDICATION

To my mother, Robbie Christiansen for her wonderfully inspirational sense of humor under adverse conditions, and for constant encouragement, support, and praise. Thanks for hanging in there with me, Mom. I am proud of you. I love you.

ACKNOWLEDGEMENTS

The completion of this endeavor was facilitated by many. First and above all I give thanks and praise to the Lord God, who is the Source of my strength. Without Him I am nothing, and without Him none of this would be possible.

I wish to thank the members of my dissertation committee for their patience, understanding, and encouragement, Dr. Anne Young, Dr. Jeanette Kernicki, and Dr. Gwen Sherwood. They all made me feel better when I was discouraged, and helped me "think bigger".

Heartfelt thanks go to friends who may never really understand how much they helped me. Thanks to Dr. Anita Giezentanner for her undying love, support, and belief in my abilities; to Terrell Smith for her love and prayers during the hard times; and to Sharon Briscoe for love, prayers, and technical support. Thanks to Dr. Dale Mannon for his wisdom, support, frequent pep talks, and helping me to "think better", and to Lauri Mannon whose friendly voice and good nature always brought me cheer. Thanks also to Dr. Tim VanDuivendyk for his support, encouragement, and consult. They are all very dear and special to me.

I wish to recognize certain groups for their understanding and support. Thanks to the members of the West University Church of Christ for their prayers and encouragement, to the Chaplaincy Services Department of Memorial Hermann Healthcare System, and to the Texas Leadership Council of Nurses Christian Fellowship.

I express my love and gratitude to my family. Thanks to Mom and Chris for

always being there for me. It means more to me than they will ever know. Thanks to my sons Eric and Luke, for knowing when I needed a hug and for trying to take care of themselves. Thanks to my daughter, Anna, who has become a beautiful young woman, for her encouragement and for taking care of the boys when I was busy.

Last, my deepest love, gratitude, and respect to my husband Mark. I would never have made it through the darkest times without his help and support. He is my hero, my encourager, my partner, and my best friend. We achieve together. This degree belongs to us both.

INTENSIVE CARE PATIENTS' PERCEPTIONS OF THE EXPERIENCE OF MECHANICAL VENTILATION

ABSTRACT

RHONDA RENAE SCHUMANN, M.S.N.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
MAY 1999

The purpose of this phenomenological study was to describe intensive care patients' perceptions of the experience of mechanical ventilation. A purposeful sample of 11 post-extubation mechanically ventilated patients was interviewed using a semi-structured interview guide, and the interviews were audiotaped and transcribed. Data were analyzed for common themes and descriptive elements using the phenomenological method. A core phase, spiritual resource connection, and four process phases: life before, lost power, in sync, and life after emerged.

Spiritual resource connection gave patients the courage, trust, and hope needed to survive the life stress and challenges, including the ventilator experience. Connection with spiritual resources empowered patients to draw on past coping strategies (life before) and to have hope for the future beyond the ventilator experience. This connection enabled patients to willingly synchronize with the ventilator's preset patterns, which allowed them greater energy to attempt self-transcendence through thinking about the past, future, and human relationships and methods of communication with staff (in sync). Disconnection from spiritual resources (lost power) occurred with fear of the unknown

or perceived mistreatment by staff, and caused patients to focus further on their own needs, pain, and inadequate communication.

As patients were told of impending extubation they experienced relief and dread at the thought of reclaiming their breathing patterns (life after). They began to put the ventilator experience into perspective, and began to feel gratitude at being alive. After extubation patients described times of physical discomfort associated with the endotracheal tube.

Findings indicated that humane, compassionate, competent care promoted spiritual resource connection, which helped patients perceive the experience less negatively and enabled them to better manage the experience. Further research is needed to determine additional methods of promoting spiritual resource connection during the ventilator experience.

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CHAPTER I

INTRODUCTION

Patients requiring mechanical ventilation experience many feelings and emotions including loss of control and powerlessness. Previously in charge of their lives, intubated patients find they no longer have control of breathing- the most basic life sustaining function. The inability to breathe without mechanical assistance causes anxiety, fear, increased discomfort, and in some cases panic (Johnson & Sexton, 1990).

The inability to use language in human interactions due to a mechanical barrier heightens the patient's sense of helplessness and fear (Bergbom-Engberg & Haljamae, 1989; Hafsteindottir, 1996). Endotracheal tubes disrupt speaking ability, leaving patients feeling alone, isolated, and without control of their circumstances. Patients' hands are often restrained to prevent accidental self-extubation, so hand motions or sign language are difficult to manage. Attempts to communicate with pen and paper, manual lettering devices, or picture boards are slow and tedious, leading to frustration and miscommunication for both patients and nurses (Stovsky & Dragonette, 1988).

Lack of patient communication leads to unmet physical or psychosocial needs which would otherwise have been fulfilled had adequate communication been possible. To deliver proper care, nurses must be able to anticipate needs of mechanically ventilated patients. Anticipation of patient needs requires nurses to gain an understanding of the patient's experience. Descriptions of patients' personal experiences can facilitate nurses' knowledge.

The problem of communication while ventilator dependent is clearly documented in the literature. However most studies are quantitative using structural data collecting techniques. (Riggio, Singer, Hartman, & Sneider, 1982; Wilson, 1987; Stovsky & Dragonette, 1988; Bergborn-Engberg & Haljamae, 1989; Simpson, Armstrong, & Mitchell, 1989; Turner, Briggs, Springhorn, Potgieter, 1990; Pennock, Crawshaw, Maher, Price, & Kaplan, 1994). While this approach is useful in gaining specific pieces of information, such structure does not permit the inclusion of important descriptive data which may surface during data collection (Field & Morse, 1985). Isolating specific pieces of the situation such as communication, pain, and weaning assumes that patients experience the situation out of context, instead of living their experience within their own reality.

The lived experience of the patient was explored through use of a qualitative methodology of the phenomenon (Marcus & Leibr, 1998). The aim of qualitative research methods permits a broader perspective incorporated into the research process. In qualitative research, participants are considered the experts regarding their experiences. The scope of experience included in the data is driven by information shared by informants.

The aim of phenomenology is to disclose the perceived experience related to one's involvement in the situation. Phenomenology, a qualitative research method, allows the researcher to explore the essence of being a patient while on a mechanical ventilator. An

understanding of the experience can be grounded in the patient's perception of reality.

With phenomenology, the phenomenon under study as personally experienced is accepted as it exists in the consciousness of the participant. The method provides a holistic approach to the subjective study of human health and wellness phenomena, and the ways that people manage those phenomena within the context of their daily lives. Instead of separating people and their care into individual acts of instruction and providing treatment, the holistic approach to nursing coincides with the phenomenological approach which can offer a foundation for the humanization of health care (Kestenbaum, 1982).

Phenomenology allows nurses to determine from patients the real experience of mechanical ventilation within the context of their lives.

While personal experiences of mechanical ventilation have been described in narrative (Castillo & Egan, 1974; Hudelston, 1977; Baier & Schomaker, 1985; Norrie, 1992), there is limited information on the patient's perception of the experience as a whole. The perception of patients who have experienced mechanical ventilation can provide information needed to give more complete nursing care in regards to this population. Knowing about patients' experiences while mechanically ventilated and understanding the issues important to those patients is necessary to develop appropriate nursing interventions which will provide the highest possible level of holistic care. When nurses are aware of the circumstances faced by patients who cannot communicate their own needs, they can offer greater support and advocacy within the context of the illness,

thereby contributing to a less traumatic patient experience.

Problem of the Study

In this phenomenological investigation, intensive care unit patients' perceptions of the experience of being mechanically ventilated were examined. Recurring patterns and themes were analyzed to derive the essence of the experience.

Rationale for Study

Mechanical ventilation is critical to the effective management of a patient whose normal breathing pattern has been compromised by chronic or acute medical conditions. By supporting ventilation and thus gas exchange, mechanical ventilation can sustain a patient for as long as possible or as necessary. Thousands of people with chronic and acute illnesses require intubation and mechanical ventilation each year (Menzel, 1997). The population of chronically, critically ill patients represents three percent of intensive care unit admissions and account for 37% of that unit's resources. They are usually elderly and frequently require mechanical ventilation for at least five days (Higgins, 1998). In addition to the chronically critically ill are patients experiencing more acute disorders which require fewer than five days on the ventilator. Both patient populations require the help of intensive care staff such as registered nurses and respiratory therapists for care and weaning procedures (Higgins, 1998).

Patients receiving ventilator assistance are poorly prepared for the experience,

even with the benefit of pre-event teaching. They are not prepared for the loss of control and the loss of communication, which are hallmarks of the ventilator experience (Stovsky & Dragonette, 1988). The high technology ventilator is essential for survival or recovery to some, but it requires patients to surrender control of their bodies and their immediate environment, and it becomes a barrier to patient and nurse interactions (Higgins, 1998).

Mechanically ventilated patients cannot communicate their perceived needs in a typical fashion. The inability to achieve a functional communication system between client and caretaker may be frustrating. In a pilot study of the patient's lived experience of mechanical ventilation, this author found that mechanically ventilated patients listed difficulty communicating as a major contributing factor to distress because they were unable to express their needs. Patients often knew when they needed to be suctioned or to have the endotracheal tube repositioned, but because of communication barriers were unable to express those needs. The American Association of Critical Care Nurses has listed nursing intervention in patients with impaired communication as a research priority for the last two decades (Riegele, Banasik, & Barnsteiner, 1994).

Ventilator patients are concerned with their own survival, but they are unable to express their survival needs. They are thus dependent on nurses to recognize those needs, and to correct problems inherent with mechanical ventilation (Johnson & Sexton, 1990). Failure to recognize patients' needs means those problems cannot be corrected.

When communication was impossible, patients felt that they had no control and that nurses should be aware of the physical and nonphysical aspects of care. Baier (1985) in relating her own personal experience of being mechanically ventilated, described occasions during which caregivers repositioned her, leaving her body pulling or compressing the tubes which sustained her life. Her inability to communicate her discomfort and desire to reposition contributed to her sense of lost control.

Critical care environments can be dehumanizing as staff care for the various life sustaining machines and attachments. Nurses working in high-technology critical care settings are required to interpret waveforms, various alarms, lab values, and other physiologic data. They must know which interventions are appropriate for which patients, and when those interventions are to be used. Nurses continually manage ventilators, monitors, wires, and intravascular lines attached to the patient. Because of the time required for managing the technology and interventions, they become proficient at caring for the technology, but may sometimes inadvertently ignore the patient (Marsden, 1990; Cooper, 1994). Time limitations make meeting more than the patient's basic survival needs difficult. The patient may be forgotten, or may be considered an attachment to the machines instead of the machines being attached to the patient. Treating the machines instead of treating the patient can threaten the patient's self-esteem (Menzel, 1997).

Like many nurses, those in critical care settings are at risk for relating to the patients as objects rather than as human beings (Cooper, 1994). Nurses are attentive to the

parts of the person which require immediate attention and may fail to view the entire person within the context of the illness, mechanical ventilation, or the critical care setting. A reciprocal nurse/patient relationship where the nurse and patient are attentive primarily to each other in a non-verbal manner can promote the nurse's understanding of the patient's needs within the critical care context, even if the person is unable to express those needs in a typical fashion.

Nurses with an understanding of the mechanically ventilated patient's situation can anticipate and meet patient needs with lessened patient communication, leading to fewer patient complications and shortened ventilation time (Goodnough-Hanneman, 1990). Decreased ventilation time can yield shorter stays in intensive care units, and increased cost effectiveness (Douglas, Daly, Rudy, Serieka, Menzel, Song, Dyer, & Montegro, 1996).

Many patient complications can occur as a result of mechanical ventilation including inadequate oxygenation resulting from a dislodged or incorrectly placed endotracheal tube, pneumothorax, pneumonia and other respiratory infections, decreased cardiac output which leads to other circulatory problems, and musculo-skeletal deficits (Pilbeam, 1992). One person described the feeling of having pressurized air in his chest, a potentially fatal condition which displaces the heart and great vessels to the unaffected side. He could not communicate his fear to the staff until one of his physicians noticed the anxiety displayed in his eyes and assessed him for complications (Hansen-Flaschen, 1994).

Limited research has been done on mechanically ventilated patients, and few studies (Gries & Fernsler, 1988; Frace, 1990) address the holistic needs of the patient experiencing mechanical ventilation. Research has focused primarily on one aspect of the experience such as communication difficulties or weaning.

Long term ventilator patients use almost one-third of intensive care resources, yet demonstrate a high mortality rate (Douglas, et al., 1996). Anticipation of patient needs can lead to shorter ventilator time as a result of rapid intervention and correction of patient problems (Goodnough-Hanneman, 1990). Decreased ventilator time diminishes the possibility of complications, improves patient outcomes, and produces greater potential for more rapid discharge from the intensive care unit. Knowledge of the patient experience while being mechanically ventilated can help nurses anticipate needs from a holistic perspective rather than from a fragmented framework. Instead of making assumptions regarding the patient's plan of care or level of comfort, nurses will have the knowledge and awareness to make a holistic and comprehensive evaluation of the possible sources of pain.

Theoretical Orientation

Qualitative research methods are used to study or explain immeasurable phenomena such as human experience. These methods are grounded in the social sciences such as anthropology, sociology, and philosophy. Using the qualitative approach researchers are able to find subjective and objective answers to questions regarding

meaning and creation of social experiences.

Qualitative research has six unique characteristics: belief in multiple realities, commitment to identifying the investigative approach most supportive of the phenomenon studied, commitment to the participant's point of view, conduct of study in a noninvasive manner in the natural setting, acknowledged participation of the researcher as the study instrument, and report of findings in a literary manner rich in participant commentary (Streubert & Carpenter, 1995). All of these characteristics guide the researcher through participation in the research and discovery of information.

While different qualitative research methods are used to answer questions important to nursing science, phenomenology is the most appropriate method for this study. Phenomenology is a philosophy and research method which attempts to study lived human experience, including a description of the meanings the experiences have for the people who participate in them (Omery, 1983).

Merleau-Ponty (1962) explicates phenomenology as the study and definition of essences such as the essence of a certain experience, and as a philosophy based on the existence and truth of that experience. Spiegelberg (1975) describes phenomenology as the philosophical movement whose goal is the investigation and description of phenomena as consciously experienced. Phenomena are the appearance of things as contrasted with the things themselves, which means that a phenomenon holds an exception to a thing or an experience.

The purpose of phenomenology is to describe or to understand the nature of a phenomenon, including the human experience (Omery, 1983). Phenomenology attempts to describe the experience of the phenomenon in question and is best suited to answer questions regarding a person's experiences. The description of the phenomenon identifies nursing interventions which are grounded in reality and can be planned and implemented based on the patient's experience. Patient's experiences are also grounded in their own perceptions of reality. Nurses and patients generally exhibit commitment to their own respective belief systems, thus their individual views of truth and reality. The lack of commitment to a common belief system relegates truth and reality to individual perceptions instead of a commonly accepted structure (Streubert & Carpenter, 1995).

The phenomenological method strives to take the researcher back to the experience so that understanding of the phenomenon can be grounded in the patient's perception of reality. This approach lends itself to an exploration and description of the essence of the experience of mechanical ventilation.

The phenomenological method is useful in obtaining subjective feelings, experiential meanings, and intentional data (Leininger, 1985). The phenomenological researcher approaches the things to be studied naively without bias or preconceptions. Data are collected in the natural setting of the phenomenon and the researcher attempts to understand the data from the participant's perspective. The researcher is the primary instrument through which the data are filtered.

The paradigm of nursing science explores concepts of human being, nursing, health, and environment. Phenomena such as being on a ventilator which involve human experience and health are of interest to nursing scientists (Parse, Coyne, & Smith, 1985). Nurses must understand what the patient experiences on a ventilator to deliver quality health care complete with holistic interventions. Knowledge of the experience can help nurses to anticipate, diagnose, and treat human responses to actual or potential health problems (Swanson-Kauffman & Schonwald, 1988).

The study is approached without hypothesis because advancing any hypothesis could promote bias. Instead, a question is asked regarding a particular human experience, and is answered by gaining a description of the experience as related by its participants. Bracketing or putting aside preconceived perceptions or explanations of the phenomenon controls researcher bias. The experience of mechanical ventilation is unknown to this researcher so few preconceived perceptions of the experience exist. Related literature is reviewed after data analysis to avoid introducing preconceptions regarding the phenomenon (Oiler, 1986).

Assumptions

The assumptions for this study include:

1. Humans experience perceptual differences based on the situational context of the moment (Paterson & Zderad, 1976).
2. It is the persons who can best relate their own lived experiences

(mechanical ventilation) (Merleau-Ponty, 1962).

Research Question

Using a phenomenological approach, the following question was asked:

1. What is the intensive care patient's experience of mechanical ventilation?

Exploration of this question should facilitate identifying common components of the phenomenon and provide a mechanism for developing a description of the experience.

Orientational Definitions

For the purpose of discussion within the text, the following terms are defined:

1. Experience is a personal situation which is described by each participant.
2. Mechanical ventilation is a life-sustaining respiratory treatment for patients who are unable to maintain an airway or breathe independently, during which patients are physically connected to the ventilator by a tube inserted into the airway through the mouth, nose, or artificial opening in the trachea.
3. Mechanically ventilated patients are hospitalized patients who are within 72 hours of extubation.

Summary

The purpose of this study was to explore and describe the experience of mechanically ventilated patients. The researcher used phenomenological methodology to describe the lived experiences of the participants. Descriptions leading to development of more compassionate

care in which patients' needs are anticipated were derived as a result of phenomenon identification. Through a deeper understanding of the experience of mechanical ventilation nurses can anticipate and meet the uncommunicated patient needs.

CHAPTER 2

LITERATURE REVIEW

The purpose of this study was to explore and describe the experience of mechanical ventilation according to the perceptions of intensive care patients. In qualitative research a literature review assists in placing the study findings in the context of what is already known. Analysis of the patients' descriptions of the experience of mechanical ventilation led to literature review regarding patient perceptions, including recollection and perceptions of intensive care experiences, stressors of mechanical ventilation, and concepts related to spirituality.

Patients' Recollection and Perception of the Experience

Mechanical ventilation is a common experience for patients with chronic problems or acute, short-term problems. Because of medications or severity of illness not all mechanically ventilated patients are aware of the processes and the difficulties entailed. Few studies have been done which attempt to determine what patients remember about the intensive care unit, specifically the experience of being mechanically ventilated. Below is a review of those studies, including a section on patients' personal descriptions of the experience.

Recollection of Mechanical Ventilation

Mechanically ventilated patients vary in their recollection of the ventilator experience due to medications or severity of illness. Studies indicated that most patients

do recall the experience, and consider it unpleasant or negative.

Bergbom-Engberg, Hallenberg, Wickstrom, & Haljamae, (1988) conducted retrospective interviews with 304 post ventilator patients between four months and two years after extubation to determine what was recalled about the ventilator experience. Two questions regarding the experience were addressed in separate writings. The first question asked whether or not patients recalled the ventilator experience. The authors found that 50% of the patients ($n = 152$) interviewed recalled the experience. Recall of the experience was not affected by time elapsed since extubation; awareness of the ventilator increased with length of intubation. The authors suggest that a shorter duration between extubation and interview may inhibit the patient's memory of the experience because of the potential residual effects of sedatives used as a regular part of ventilator treatment.

In the second article based on the retrospective interview of 304 mechanically ventilated patients (Bergbom-Engberg and Haljamae, 1988) asked what patients recalled about the ventilator experience. They found that 71% ($n = 113$) of 158 patients who recalled the ventilator experience remembered feeling secure with the surrounding events while 28% ($n = 45$) felt insecure. Contributing to the patients' feelings of security were synchronizing breathing patterns with the ventilator, presence of a nurse who appeared to be expert in providing care, and the patients own conviction of surviving which included strong feelings of hope and belief in God. Adding to patients' feelings of insecurity were inability to trust or adapt to the technology, lack of trust in the nurse, communication difficulties, and conviction of impending death. Pearson correlation coefficients showed

significant relationships between feelings of insecurity and the inability to communicate ($r = 0.30$; $p < 0.001$), inability to synchronize with the respirator ($r = 0.28$; $p < 0.001$); and to resume spontaneous respiration ($r = 0.19$; $p < 0.05$).

Simpson, Armstrong, and Wilson (1989) interviewed 92 intensive care and critical care patients and found that 64% ($n=59$) recalled the intensive care experience while 36% ($n=33$) did not recall the experience. The researchers administered an open-ended questionnaire to determine the subjects' memory of the reason for admission, major sources of information, care provided, and impact of the critical care experience. Patients recalled physicians as the greatest source of information and nurses as performing most of the care. Contrary to the findings of other studies (Bergbom-Engberg, Hallenberg, Wickstrom, & Haljamae, 1988; Green, 1996), most patients considered the critical care experience as positive or neutral though several listed negative stressors such as pain, sleeplessness, fear, anger, and loss of control.

Green (1996) interviewed 26 post intensive care patients to determine memory of their stay and their coping abilities with the experience. Study participants were asked 12 questions regarding the experience, and the responses underwent thematic content analysis. Ninety-two percent ($n = 24$) of the patients recalled the experience, which is a greater percentage than those listed in other studies (Bergbom-Englberg, Hallenberg, Wickstrom, & Haljamae, 1988; Simpson, Armstrong, & Wilson, 1989). Themes arising from the analysis indicated that most of the patients had unpleasant memories of the intensive therapy unit, including pain or discomfort, presence of tubes, feelings of panic or

fear, and disorientation. Most patients did not remember the nurse's names though they did remember detailed information given by the nurses. Patients also described memories of communication difficulties, psychoses, and noise.

The previous studies (Bergbom-Engberg, Hallenberg, Wickstrom, & Haljamae, 1988; Bergbom-Engberg & Haljamae, 1988; Simpson, Armstrong, & Wilson, 1989; Green, 1996) have shown that the majority of patients studied recalled the intensive care or ventilator experience. Many patients considered the experience unpleasant. Recall of the experience included patient awareness of the ventilator, feelings of security or insecurity, pain, communication difficulties, sources of information, and technical care.

Perceptions of Mechanical Ventilation

Many intensive care patients perceive the experience of mechanical ventilation as unpleasant and negative. Factors contributing to the negative perceptions are communication difficulties, fear, pain, immobility, and loss of control. The following section discusses patients' perceptions of mechanical ventilation. Patient descriptions of the experience are followed by studies of patient's perceptions.

Castillo and Egan (1974) described the experience of long term mechanical ventilation from the perspective of a polio patient. Egan had spent much of his life on a ventilator, and shared with the medical community perceptions of his personal experience. Included in the description were physical reactions to the ventilator, feelings of indignity at the situation, potential psychological disturbances, communication difficulties,

importance of staff truthfulness regarding the patient condition, importance of staff proficiency in executing procedures, and need for respectful treatment. Egan listed several suggestions for improvement of care by nurses and respiratory therapists such as practicing proficiency in respiratory procedures, communicating with patients, and treating patients and families with respect.

Hudelston (1977) wrote about the experience of mechanical ventilation, but does not indicate whether these data were obtained from personal experience or by research. The author described crisis management, communication difficulties, drug induced visual disturbances, restraints and immobilization, psychoses, and the need for staff interaction. Prominent in the description is the patient's perceived loss of control with each procedure and the situational stress caused by the ventilator experience.

One of the most detailed accounts of being mechanically ventilated is a highly successful narrative from Baier and Schomaker (1985). These authors describe Baier's experience as a patient with Guillain-Barre syndrome, during which time she lay "imprisoned" in the intensive care unit. The description was based on her personal thoughts during the ventilator time and on entries from her husband's diary. Baier describes feelings of loss of control, fear, panic, humiliation, and feelings of isolation. She discussed communication difficulties, physical pain and discomforts, staff insensitivity, hospital territorial wars, and inhumane treatment. Baier and Schomaker emphasize the need to be treated as a human being, the importance of time orientation in maintaining a reality base, staff communication, the value of friends, family, and visitors, and the

importance of her faith in surviving the experience.

Frace (1990) interviewed three patients to learn their perceptions of the mechanical ventilator experience. The author included the structured interview questions as well as patients' response to each question. Patient concerns included inability to communicate, forced dependence on others, use of restraints, increased anxiety, and the threat to survival. The predominant need of the patients was to be able to communicate with the staff, and for the staff to communicate and explain procedures to them.

Norrie (1992) interviewed a former intensive care patient nine months after the patient was discharged from that unit. Suffering from Guillain-Bare syndrome, the patient was alert during the 15-day intensive care stay. Through narrative the participant shares that the most valuable aspect of nursing care received was staff communication and reassurance.

Patient descriptions of the ventilator experience are similar to these accounts. Prominent within each description was the stress caused by communication difficulties while intubated. Other commonalities within patient descriptions are need for human interaction, need for explanations and orientation, and feelings of loss of control.

In an exploratory study, Gries & Fernsler (1988) interviewed five men and four women using a 14 item questionnaire about their perceptions of stressors associated with mechanical ventilation. Stressors were classified according to Neuman's model of nursing with its total person approach, and were coded as interpersonal physiologic, intrapersonal psychosociocultural, interpersonal, and extrapersonal. Participant responses to the

questions were classified as positive, neutral, or negative, where negative responses were considered indicators of stressful experience. Study participants identified a total of 13 stressors. Investigators found that there was no apparent relationship between length of time on the ventilator and the number of stressors the participants perceived, between age and number of stressors, or between genders in number of stressors indicated. Perceived stressful experiences included communication problems, insufficient explanations by staff, activity restrictions, and discomfort associated with the endotracheal tube. Perceived nursing interventions that lessened the stress of the experience were reassuring words and displaying a caring manner. These findings are similar to those of Bergbom-Engberg, et. al. (1988).

Turner, Briggs, Springhorn, and Potgieter (1990) found in their study of 100 post intensive care patients that 94 described the intensive care environment as friendly and caring. Pain from incisions, fractures, procedures, endotracheal tubes, and immobility was considered stressful by 22 (22%) of the patients. Sixty-eight of the 100 patients (68%) had been on a ventilator during their intensive care admission. As with the findings of Gries and Fernsler (1988), 30 (44%) of the ventilator patients found tracheal suctioning to be moderately to severely unpleasant. Other stressors included noise level, family concerns, and ward rounds.

Jones, Hoggart, Withey, Donaghue, and Ellis (1979) interviewed 100 consecutive patients between three and seven days after intensive care discharge to learn their perceptions of the intensive care unit. All subjects within the sample had been patients in

the intensive care unit. Twenty-two percent of those 100 patients ($n=100$) had been on a mechanical ventilator, and 32% of the twenty-two ($n=7$) recalled the experience. Twenty-three percent of those patients ($n=5$) described sleep problems related to the presence of the endotracheal tube, and 14% ($n=3$) remembered feeling discomfort or pain related to intubation. None of the patients recalled other stressors while on the ventilator. These findings related to intubation are similar to those of Gries and Fernsler (1988), and Turner, Briggs, Springhorn, and Potgeiter (1990), but are not as inclusive of perceptions as the patient descriptions.

This section (Castillo & Egan, 1974; Hudelston, 1977; Jones, Hoggart, Withey, Donaghue, & Ellis, 1979; Baier & Schomaker, 1985; Gries & Fernsler, 1988; Frace, 1990; Turner, Briggs, Springhorn, & Potgieter, 1990; & Norrie, 1992) described personal or patient perceptions of the ventilator experience. Descriptions include communication difficulties, importance of staff communication, immobility and paralysis, loss of power and dignity, visual disturbances, pain and discomfort, and loss of orientation. Patients stated that staff communication was important to their care.

Stressors of Mechanical Ventilation

Studies have been completed to determine what factors produce stress among mechanically ventilated patients. Below is a review of those studies including sections on communication, psychological stressors, and physical stressors.

Communication

Communication is vitally important to survival. The ability to communicate is a source of power in today's world. Inability to communicate renders persons nearly powerless within their circumstances, and contributes to feelings of fear, isolation, and lost control. Because they are unable to communicate, patients perceive communication struggles as a major stressor within the ventilator experience. Mechanically ventilated patients feel the powerlessness, fear, isolation, and lost control inherent in lost communication. The following studies discuss patients' difficulties with communication and interventions developed to manage communication difficulties.

In an exploratory study, Menzel (1997) found that mechanically ventilated patients experienced fear and worry related to the inability to communicate while intubated. They tested a convenience sample of 29 ventilator patients drawn from four intensive care units to determine the intensity of emotional responses related to communication difficulties while intubated as compared to intensity of emotional responses after extubation. Patients were assisted in completing the anger and worried/fearful subscales of the Emotion Scale and Ease of Communication Scale while they were intubated, then independently completed the same scales seven days post extubation. Paired t-tests were used to compare the scores at intubation and after extubation. Results indicate no significant differences in mean scale scores for communication during intubation and after extubation, though more than one-third of the patients reported changes in some of the responses between intubation and extubation. The change in scores suggests that patients initially

experienced and later recalled moderately intense feelings of worry and fear associated with the inability to communicate. Pearson product moment correlations showed no significant relationships between the change scores of before and after extubation, and demographic (age, sex) or situational variables (number of days intubated, number of days extubated, and reason for intubation). The authors suggest that the sample size of this study was too small to elicit significant correlations.

Pennock, Crawshaw, Maher, Price, and Kaplan (1994) completed a cross-sectional survey of 127 post coronary artery bypass surgery patients to determine what they consider most stressful and least stressful within the critical care experience. Patients were interviewed and given an instrument developed for this study within 48 hours of discharge from the intensive care unit. The developed instrument included a list of stressors compiled from the literature, and underwent content validity with a panel of intensive care nurses and physicians. The authors stated that the instrument content validity was continuously evaluated, but did not include a content validity index estimation. The same investigator administered the instrument, and only to patients who had no visitors or conflicting medical procedures to minimize variability in scores. Responses were analyzed using a one way analysis of variance, and significant difference was measured using the Newman-Keuls multiple range test. Investigators found that the most stressful experiences in the intensive care setting were intubation and inability to communicate, which is consistent with the findings of other studies (Menzel, 1997; Hafsteindottir, 1996; Parker, Schubert, Shelhaner, & Parrillo, 1984). Patient comments were solicited as part of

instrument content validity and were summarized into narrative format. Summaries were grouped into useful, discrete categories that included praise for nursing care and the need for a communication system to be used while they were on the ventilator.

Hafsteindottir (1996) interviewed eight patients who had been mechanically ventilated to determine their perceptions of communication while on the ventilator. Colaizzi's method of phenomenological analysis was used to gain descriptions of the experiences. The participants described communication experiences as negative, tiring, and exhausting. They described the feelings of giving up while they felt their communication was impaired. Participants discussed the importance of staff communication and explanations, and the importance of the presence and support of family.

Similar views were reported by an intensive care nurse who was mechanically ventilated for a three week period due to severe infections resulting from chronic illness (Parker, Schubert, Shelhamer, & Parrillo, 1984). After extubation the nurse-patient shared the experience of mechanical ventilation and paralysis. She stressed the importance of communication, explanation, and environmental orientation. Although the patient was a nurse and had performed the same nursing tasks which she experienced, she stated she would have benefited from explanation with each task performance. While paralyzed she became disoriented and required re-orientation more than eight times a day. She expressed the need for reassurance regarding her condition, loss of bodily function, and paralysis.

Intensive care staff utilize different methods to decrease the stressful effects of lost communication. In a quasi-experimental study of 40 post cardiac surgery patients Stovsky, Rudy, and Dragonette (1988) found that planned communication in which the patients were familiarized with the communication board prior to surgery increased patient satisfaction with the post operative ventilator experience. The group with unplanned communication was not taught to use the communication board prior to surgery, and did not have access to the board while on the ventilator. Instruments used to determine the effectiveness of the communication board were an open-ended patient interview, a nurse bedside assessment tool, a patient and nurse satisfaction questionnaire, and a visual analog scale on satisfaction with communication. Content analysis of patient interviews supported the findings of the independent t -test for the patient satisfaction questionnaire, which indicated increased patient satisfaction with use of the communication board ($t=2.09$, $p=0.05$, $n=35$). Most patients in the experimental (planned communication) group stated that the picture board had been useful to them while on the ventilator. The authors determined that a planned communication method increases patient satisfaction in the early postoperative period.

Another communication technique is touch. Verity (1996) performed a review of literature regarding the effects of touch and found that mechanically ventilated patients valued touch by the staff as important to communication. Definitions of touch include comforting touch which is used to help patients cope with stressors, task touch which is used with procedures, and affectionate touch which indicates recognition, acceptance,

protection, and concern. The author stated that intensive care environments offer limited communication opportunities for patients, which could lead to increases in anxiety and pain. Verity suggested that use of touch as a communication technique could decrease levels of anxiety and pain, thereby reducing the need for other interventions. Verity indicated that touch used appropriately as communication can promote recovery.

These studies (Menzel, 1997; Pennock, Crawshaw, Maher, Price, & Kaplan, 1994; Hafsteindottir, 1996; Hafsteindottir, 1996; Parker, Schubert, Shelhamer, & Parrillo, 1984; Stovsky, Rudy, & Dragonette, 1988; & Verity, 1996) demonstrate the stress caused by lack of communication or inability to communicate. Findings promote the use of touch, communication boards, and frequent environmental orientation when caring for ventilated patients.

Psychological Stressors

Intensive care units are typically bright, busy, and noisy which causes some patients to experience sensory overload. These factors in combination with patients compromised physiologic state can contribute to a patient condition known as intensive care syndrome. Visual and auditory hallucinations and disruption in normal interpretation of the environment characterize intensive care syndrome. Patients may not experience stressors to that extreme, but may have symptoms to a lesser degree.

In a literature review regarding intensive care syndrome for the years 1950 to 1995 Granberg, Bergbom-Engberg, and Lundberg (1996) found that there was no one

particular cause. The syndrome is a process to which patients may be predisposed, and which has precipitating factors. Predispositional factors may include worry/fear, lack of control, and feelings of loneliness and sorrow. Precipitating factors include communication difficulties, lack of close relationships, isolation, fatigue, and tension. Patients who are predisposed and who experience the precipitating factors develop altered body perceptions, have difficulty relaxing, become disoriented and confused, and lose perception of time. During the continuing process patients lose contact with reality, experience nightmares and hallucinations, and have feelings of aggression, despair and withdrawal. They become fearful and horrified, and then exhausted, they resign to the syndrome. Authors suggested that research should be aimed at prevention, and at developing interventions for promoting recovery when patients have experienced intensive care syndrome.

Likewise, McCartney and Boland (1994) indicated the root cause of anxiety in mechanically ventilated patients is the result of the interaction of multiple factors such as serious medical illness, central nervous system dysfunction, drugs or medication, and the impact of medical procedures such as intubation. Distinction should be made between anxiety, which is a state of apprehension, increased motor tension, and autonomic arousal; and delirium, which is a reversible organic mental syndrome caused by severe illness, because the treatment for one may adversely affect the other. The goal of treating delirium is to eliminate its medical and pharmacological causes such as respiratory distress and the resulting anxiety. Ventilator patients are anxious because of the associated

respiratory distress. Patients being weaned from the ventilator experience an exacerbation of anxiety which may be caused by fear of unsuccessful weaning. Anxiety can spiral to delirium rendering the weaning patient unable to cooperate. To gain cooperation, patient anxiety must first be treated.

Wilson (1987) studied 38 patients admitted to a surgical intensive care unit regarding their perceptions of stressors associated with intensive care unit admission. The purpose of the study was to determine whether patients with normal psychological response (NPR) perceived stressors differently than patients with an impaired psychological response (IPR). The patients were first assessed using a mental status exam to determine whether they had IPR or NPR. Forty-two percent of the patients ($n=16$) were found to have NPR while 58% ($n=22$) were classified as IPR. Patients were asked to complete the patient stressor scale, a four point Likert scale developed by the author for this study, where "0" was considered not stressful and "3" was very stressful. The patient stressor scale was developed based on the literature and underwent content validity for clarification and test-retest reliability during a pilot study. Items with a content validity index of 0.80 were included in the instrument, and the reliability coefficient for the instrument was 0.80. The IPR group identified four of the stressors as more intense than the NPR group: too much noise, time disorientation, staff discussions about the patient rather than to the patient, and being examined by several doctors and nurses. The stressors considered most bothersome were pain, immobilization, sleep disturbance, ventilator or oxygen therapy, surgery, and having too many tubes. Perception of greater

intensity of stressors by the IPR group is similar to the findings of Granberg, Bergbom-Engberg, and Lundberg (1996) who stated that intensive care syndrome has predispositional factors.

Riggio, Singer, Hartman, & Sneider (1982) designed a study to compare the perceptions of anger, anxiety, and frustration in the care of respirator patients as perceived by 21 patients, 17 of their families members, and 31 of the staff. Interviews and three different questionnaires, one for patients, one for family, and one for staff designed for this study were used. Questionnaires contained a series of 15-point semantic differential-type rating scales dealing with aspects of respiratory care situations. Fifty-two percent of 21 patients ($n=11$) reported having communication difficulties that contributed to patient perceptions of psychosocial stress. Patients experiencing communication difficulty also reported strong feelings of anger, anxiety, or frustration, while patients not reporting communication difficulty were not as likely to report these feelings during intubation. This finding indicates the extreme emotional stress which can be brought on by the inability to communicate.

The study also examined 17 family members and 31 staff members regarding their perceptions of the patient's psychosocial care issues. Family and staff tended to report more extreme perceptions of problematic patient issues than did the patients. Staff perceived patients as having greater communication, memory, and negative emotion problems than did the patients or family. Patients and family stated that the staff were providing adequate care for the patients. The authors indicated that the same situation was

perceived differently by patients, family members, and staff. Though the patients were experiencing the intensive care setting and the mechanical ventilator, the authors questioned the accuracy of patients' perceptions. They stated that the patients might be in a process of denial, so may not remember traumatic events as they occurred.

The literature (Granberg, Bergbom-Engberg, & Lundberg, 1996; McCartney & Boland, 1994; Wilson, 1987; & Riggio, Singer, Hartman, & Sneider, 1982) explored the psychological effects of mechanical ventilation on intensive care patients. Patients experienced intensive care syndrome, anxiety, and delirium. These effects were perceived with greater intensity in patients who are predisposed to illness caused by psychosocial stressors.

Physical Stressors

Mechanically ventilated patients experience physical pain and discomfort related to the presence of the endotracheal tube, medical or traumatic conditions, treatments, immobilization, and other conditions. These physical stressors enhance and are enhanced by other stressors such as communication difficulties and psychological stressors.

Johnson and Sexton (1990) interviewed 14 patients who were one to six months post extubation. Communication difficulty was found to be the major stressor among these patients. They found that 12 of the 14 participants (86%) listed pain and discomfort as the second most common cause of distress during mechanical ventilation. Authors noted that the pain was due not only to the presence and care of the endotracheal tube, but was also a result of uncomfortable body position, infrequent position changes, restraints,

tugging of ventilator tubing, and arterial blood gas sticks. A third major stressor occurred as patients attempted spontaneous respiration, which led to “bucking” the ventilator.

Bergbom-Engberg and Haljamae (1989) found in a study of 158 post-ventilator patients that 36% ($n=57$) complained of or remembered pain or discomfort. Patients were questioned regarding discomforts associated with communication, intubation, positioning, fear and anxiety, sleep, suctioning, synchronization, and difficulties in resuming spontaneous breathing. Inability to talk and the resulting feelings of isolation increased periods of fear and panic, playing an important role in psychosocial discomfort. Suctioning disturbed respiratory patterns and interfered with synchronization, leading to arousal of emotions such as insecurity. Similar to the findings of Johnson and Sexton (1990), the most common complaints of physical discomfort were due to positioning and immobilization. Physical complaints intensified the psychosocial manifestations experienced by the patients.

Likewise, Baier and Schomaker (1985) described the physical symptoms which Baier experienced while on the ventilator. Pain and discomforts experienced included mouth dryness and pain, soreness from maintaining the same body position for long periods, fatigue from communication attempts, and pain from treatments or procedures. Because of the prolonged period of immobilization, she developed calcium deposits in her joints which contributed to the pain.

The previous writings (Johnson & Sexton, 1990; & Bergbom-Engberg & Haljamae, 1989; Baier & Schomaker, 1985) have shown the effects of physical stress on

mechanically ventilated patients. Authors noted stressors caused by pain from the endotracheal tube and immobility, stress from the inability to communicate, and attempts to breathe spontaneously.

Spirituality and Spiritual Care

The spiritual dimension profoundly influences health (Boland, 1998). The study of the nature of spirituality is increasingly more common as researchers are more aware of the patient's spiritual dimension and its relation to overall health and well being. This section will focus on spirituality including definitions of terms related to spirituality and religion, and the nature of spiritual needs and care.

Spirituality

Spirituality is a broad concept describing the part of all human persons which gives life, animation, meaning, purpose, hope, and faith. The human spirit is that which connects in relationship with oneself, with others, with nature, and with God as God is perceived by the person. As part of the complete person, spirituality is important to well being because the person is physical, mental/emotional, spiritual, and social. If one aspect of the person is disrupted, then all are disrupted. Therefore, if the person's spiritual dimension is weakened or diminished, so are that person's physical, mental/emotional, and social dimensions. Likewise, if the person's physical, mental/emotional, or social dimensions are weakened or diminished, so is the person's spiritual dimension. Spirituality is difficult to measure, as are outcomes of spiritual growth or care.

Though the terms religion and spirituality are often used, they are not the same concept. Religion is the manner in which persons express spirituality. It describes the mechanics of relationships with oneself, others, nature or God including specific beliefs and rituals of worship. Religious beliefs and practices such as prayer, sacred readings, or sacraments provide strength and comfort to persons who are ill or distressed, and the strength drawn from religious practices can enhance their general well being by helping the spiritual dimension. Persons often increase their religious practices during times of illness or crisis because the increase of spiritual strength brought by their religiosity.

Authors agree that spirituality and religion are different concepts, and are in agreement regarding many of the attributes of each concept. However, because of its broad and abstract nature, no universal and operational definition exists for the concept of spirituality. Most definitions of spirituality describe the search for meaning and purpose as most prominent within the person's spiritual pursuits.

In a literature review on spirituality, Burkhardt (1989) discovered multiple uses of the term. Spirituality has a broad context and can be described as one's being and being more aware of one's life source as indicated by sense of peace, hopefulness, creativity, joy, enthusiasm, courage, changeability, reverence, awe, humor, serenity, sharing with others, finding meaning in struggle and suffering. Spirituality involves a reflection on and coming into relationship with one's experiences.

Nagai-Jacobson and Burkhardt (1989) described spirituality as a broader concept than religion. Spirituality involves a personal quest for meaning and purpose in life; relates

to the inner essence of a person, is a sense of harmonious interconnectedness with self, others, nature, and an Ultimate Other; and is the integrating factor of the person.

Stoll (1989) defined spirituality as the core of one's being that is concerned with meaning and purpose in life. It is the intangible motivation and commitment directing toward ultimate values of love, meaning, hope, beauty, and truth. Inherent within the spirit are the resource dimensions courage, trust, and hope. Courage does not imply absence of fear, rather facing one's fear. It is needed to persevere in face of innumerable odds. Trust is the inner stability required to meet the demands of change. Hope is the motivator to move people toward new options. Hope is never generated in isolation but is related to the expectation of assistance based on past personal experience. Connection with these resources provides an internal support system giving persons the strength and ability to cope with and manage the pressures of everyday life. Disruption in the connection between persons and their spiritual resources can lead to fear, mistrust, and hopelessness.

Oldnall (1996) stated that a person's spirituality may be dependent on the ability to give and receive such human elements as touch, listening, committed presence, love, and trust. The spirit is considered the driving force which gives meaning to life and creates a set of values and beliefs to govern a person's conduct.

In a literature review of the concept of spiritual relationships, Walton (1996) discovered that based on the attributes and perceptions noted in the literature, a spiritual relationship was operationally defined as a relationship to self, others, a higher power, or

nature in which one behaves humanistically, has a sense of responsibility and personal identity, and describes the relationship as producing intimacy, wholeness, and wellness. Commonalties in the descriptions of spiritual relationships were the relation of connectedness to others and one's spiritual well-being, intimate self-reflection to enhance personal knowing, assistance with coping and problem solving, importance of relationship with God in recovery, enabling transcendence. The author noted that the depth of intrapersonal relationship to one's self is directly related to the depth of one's spiritual relationships with others, a higher power, or nature.

Likewise, Sherwood (1997) stated that a person's deepest need is to overcome separateness and establish relationships. Humans have an innate desire to connect and establish relationships. Connection is defined as a dynamic term making contact, joining together, and linking through association with others. It is a harmonious way of making contact, being in harmony with the elements of one's internal and external environment.

Connectedness is important not only to relationships, but also to many aspects of spirituality. Haase, Britt, Coward, Leidy, and Penn (1992) simultaneously studied the concepts of spiritual perspective, hope, acceptance, and self-transcendence to refine the definitions of each concept. Simultaneous concept analysis was used to clarify each concept in relation to the others. As a result, critical attributes, definitions, antecedents, and outcomes of each concept were generated. Concept matrices were examined for emergence of a central theme. Connectedness with others emerged as an antecedent of hope, a critical attribute of spiritual perspective, and a consequence of acceptance and

self-transcendence. The authors viewed connectedness as more encompassing than social support, rather as a shared and meaningful relationship with another person, a spiritual being, nature, or one's inner self.

Emblen (1992) reviewed nursing literature from 1963 to 1989 for definitions of spirituality and religion. Concept analysis was performed and keywords or those most frequently used, for each concept were listed. Only the word "personal" appeared on both lists, meaning therefore that the concepts were not the same. According to the list consensus, spirituality refers to a dynamic, a principle or an aspect of the person that relates to God, other persons, or aspects of personal being or material nature

These authors describe religion in relation to spirituality. Burkhardt (1989) defined religion as a belief system, a product of the rational mind which has to do with the conceptualization of spiritual experience that it takes the collective spiritual experiences of people and forms them into a system. It is the way persons practice their spirituality. Emblen (1992) stated that religion refers to faith, belief, and practices that nurture a relationship with a superior being, force, or power. There is concern that confusion between the terms spirituality and religion limits the definition of spiritual needs, making difficult nurses' ability to recognize and meet those needs. Oldnall (1996) stated that each person has spiritual needs regardless of belief in organized religious practices.

In a descriptive study of 25 cancer patients and nurses Sodestrom and Martinson (1987) found that 88% ($n=22$) used a variety of spiritual activities and resource persons such as clergy to cope with their disease. Semi-structured interviews were completed to

determine the type and frequency of patient's use of spiritual activity and to determine if nurses recognized use of spiritual resources versus psychosocial coping strategies. Though no index estimation was listed, content validity of the interview was established by literature review and expert panel which judged the patient and nurse interviews to adequately represent the spiritual domain. Spirituality was found to play an important role in patient coping strategies. Patients reported an increase in awareness and practice of their spiritual beliefs and coping strategies since diagnosis, and participated in such activities as prayer, keeping religious objects on hand, listening to religious programs, reading and memorizing the Bible, attending religious services, and requesting communion or other sacraments. Spiritual resources persons included family, clergy, friends, nurses, and physicians. Findings also showed that most nurses were able to recognize patient's use of spiritual coping strategies. Authors suggest that nurse recognition of spiritual activities and personal resources can increase the possibility that nurses will provide holistic care.

Use of spiritual coping strategies contributes to a patient's sense of well being. Clark, Cross, Deane, and Lowry (1991) interviewed 15 cancer or heart disease patients to determine factors contributing to the patient's sense of well being or hope while in the hospital. Patients participated in structured interviews regarding their beliefs about meaning and hope in times of crisis, and their responses were analyzed for common themes. Findings indicate that the most significant contribution to patient's sense of well being or hope was nurse presence and care giving activities. Other findings included the

importance of trust developed for the nurse who paid close attention to every detail, meaningful support systems which provided a human link between the nurse and patient's life before hospitalization, and showing respect for personal beliefs.

The previous writings (Burkhardt, 1989; Nagai-Jacobson & Burkhardt, 1989; Stoll, 1989; Oldnall, 1996; Walton, 1996; Sherwood, 1997; Haase, Britt, Coward, Leidy, & Penn, 1992; Emblen, 1992; Sodestrom & Martinson, 1987; & Clark, Cross, Deane, & Lowry, 1991) offer descriptions of concepts related to spirituality and religion, and provide evidence of the important role of spirituality in healing and well being. These authors noted that the terms spirituality and religion are not interchangeable, and that nurses can overlook spiritual needs and care by limiting patient assessment to the religious needs instead of the broader spiritual needs.

Spiritual Distress and Spiritual Care

Spiritual distress can occur in at any point in life, whether in good times or bad, during illness or health. It is a time of questioning one's purpose in life, of trying to find meaning in life situations, and of attempting to put experience into perspective. Persons may manifest spiritual distress in deeply spiritual ways such as despair or uncertainty with questioning life and death issues, or they may have psychosocial indicators such as anger or denial. Though anyone can experience spiritual distress at any time, it commonly occurs in critically ill patients who are facing their own mortality.

Nursing students are taught very little regarding the spiritual dimension, and many

are uncomfortable with spirituality or the idea of providing spiritual care. Oftentimes nursing schools devote a few content hours to the spiritual realm, and may teach basic assessment techniques, but instruct nurses to intervene in spiritual issues by providing psychosocial care.

Nurses are better able to determine patients' spiritual distress and the need for spiritual care because they are with patients more than any other health profession. They can assist patients in discovering and facing their needs, and in meeting the patients' needs for spiritual care. Persons are holistic, including physical, mental/emotional, spiritual, and social aspects, so are affected by needs felt in each of those realms. Providing spiritual care through the use of self, referral to clergy, or other spiritual interventions can promote holistic healing since all aspects of the person are integrated to make the whole.

Piepgras (1968) wrote one of the first nursing articles regarding spiritual care. In it the author encourages nurses to bring the patient to a realization that spiritual longing is acceptable and not to dodge such discussions with patients who have the desire to talk about spiritual needs. Piepgras lists indications for spiritual help as a patient indicating a need to discuss spirituality, emotional cues, being faced with an inevitable undesirable outcome of illness, an inescapable predicament which can not be resolved, and an adolescent questioning meaning and purpose in life. Recommended is that nurses be familiar enough with their own faith beliefs to serve as a resource to others, be understanding listeners, and attempt to keep the patient's mind off death. Piepgras concluded that consistent suppression of spiritual need leads to spiritual death.

Hospitalized patients may feel alone and isolated. Dickinson (1975) stated that the human spirit needs a human relationship and that human beings cannot live in isolation from other humans. The spiritual aspect of nursing is built on the humanity of people especially during illness when one's mode of living, character, commitment, and answers to the ultimate life and death issues are called into question. According to Dickinson, immediate and unlimited nurse availability is crucial to the ill patient, especially in the hospital where loneliness and insecurity are prevalent causing the patient's dignity and identity to suffer. The author concludes that spiritual nursing care means offering the nurse's own life experience to others by being herself and providing awareness, understanding, care and sensitivity to each patient.

In an article intended to encourage critical care nurses to recognize the importance of patient's spiritual concerns, Shaffer (1991) stated that patient's with life-threatening illness confront issues of human weakness, pain and suffering, and the relationship between oneself and deity. Shaffer suggests that these patients may need help in their search for something in which to believe and hope. Manifestations of spiritual distress may affect the outcome of the illness whether it is recovery or peaceful death. The author suggests that a spiritual assessment be performed along with the psychosocial assessment of each patient. Nurses should be skilled enough in assessment to respond to small indications of spiritual distress, which can include search for meaning and purpose, hopelessness, despair, fear, anxiety, depression, and apathy.

Smucker (1996) studied the experience of spiritual distress using a

phenomenological approach. Five men and five women from the general population were interviewed for approximately one hour each regarding their experience of being concerned with the meaning of life, death, and beliefs. The audiotaped interviews were transcribed verbatim and analyzed. Results indicate that the experience of spiritual distress is a process over time that has the identifiable phases which fall into the metaphor "web of life". The first phase is breaking the web of life during which an event suddenly breaks into a person's life. The second phase is rebuilding the web of life during which the person comes to some acceptance of the event and is able to find its meaning through positive actions in the world. The author defined spiritual distress based on this study as an uncomfortable experience of spiritual and/or existential struggle within which there is potential for growth. The stated definition implies that spiritual distress is more than a problem, rather a potential for growth.

Holistic nursing practice can enable spiritual care whether or not spiritual distress is present. Oldnall (1996) reviewed the nursing literature from 1980 to 1994 in an attempt to determine the definition of spirituality as it relates to holistic nursing practice. It was determined that nursing theorists and educators devote too little emphasis to the concepts of spirituality and holistic nursing, and that student nurses should receive education regarding the spiritual dimension as part of their regular training. Shaffer (1991) stated that nursing interventions for spiritual distress in critically ill patients include nurse presence and empathetic listening, therapeutic touch, prayer, referral to clergy, and total person caring.

Connecting in relationships is an important aspect of spirituality and is also important in providing spiritual care. According to Sherwood (1997), connection with others takes courage and a willingness to risk rejection or pain. Though connection is not always possible, it is the predecessor of caring, because caring implies human connection. Caring is founded on the principles of individuality and the transcendence which occurs between caregiver and care receiver, presence which emphasizes and implies a harmonious connection with the other at "soul level", personal knowing of the other's need which arises only from existential presence, and interacting which enhances growth and enables the other to be stronger. Establishing caring connections with others requires that the nurse be available, value uniqueness of the other, and trust others. Interpersonal connections offer patients care and hope, which promote patient growth and healing.

Likewise, Nagai-Jacobson and Burkhardt (1989) stated the importance of recognizing all humans as spiritual beings because spirituality is one aspect of the complete human being. Holistic nursing involves the spirituality of the nurse and the client and is transformational for both. Nurses who understand the importance of interconnectedness with one's self recognize the significance of the person's past, present and future, and the significance of events, relationships, and experiences in shaping the person's understanding of life.

Clark, Cross, Deane, and Lowry (1991) suggested that nurses presence and caregiving activities play a significant role in the spiritual well or hope of critically ill patients. Nurses should strive to establish a trusting relationship, provide and facilitate a

supportive environment, respond sensitively to patients' belief systems, integrate spirituality into the quality assurance plan, and take ownership of the nurse's role in health care to provide quality care and enhance patient spiritual wellbeing.

Wright (1998) takes the need for nurses to provide spiritual care a step further. Spiritual care involves helping people identify and develop their spiritual perspective, promoting personal awareness of spirituality and its components, and helping people meet their own spiritual needs. Nurses believing in the concept of a holistic person have an ethical responsibility for providing spiritual care but are reluctant to do so because of lack of education in spirituality, fear of invading the patient's privacy, lack of time, and lack of awareness of one's own spirituality. Failure to provide spiritual care violates the ethical principles of fidelity, beneficence, nonmaleficence, autonomy, and advocacy. Since spirituality is an important aspect of wellness it is vitally important in ethical nursing care. Nurses play a key role in helping patients find hope and meaning in life, so professional and ethical obligations compel nurses to develop skills in providing spiritual care.

The previous authors (Piegras, 1968; Dickinson, 1975; Shaffer, 1991; Smucker, 1996; Oldnall, 1996; Sherwood, 1997; Nagai-Jacobson & Burkhardt, 1987; Clark, Cross, Deane, & Lowry, 1991; and Wright, 1998) discussed the importance of spirituality in healing, identifying spiritual needs, and providing spiritual care. All emphasized the need for interhuman relationships in providing spiritual care. One author (Wright, 1998) stated that nurses have an ethical obligation to provide spiritual care.

Summary

Patient recollections of mechanical ventilation tend to be negative, although positive aspects regarding nursing or staff care are noted. Some authors discussed possible interventions aimed at reducing the stress associated with the experience. Stressors during the experience of mechanical ventilation included communication difficulties, lack of orientation, feelings of isolation, fear, and pain. Maintenance of communication and patient orientation was key to promoting patient well being.

As individuals cope with illness, spirituality can serve as a resource. Courage, hope, and trust are evident as patients work to find meaning in the experience within their own life perspective and beliefs. Intrapersonal connection helps the with care providers. Nurses can promote spiritual connection by providing compassionate care which focuses on the whole person, including body, mind, and spirit. Though many nurses are uncomfortable with spiritual assessment and care, they have an ethical obligation to do so. Providing spiritual care promotes healing as patients explore hope, meaning and purpose in life.

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

A phenomenological approach was used to explore and describe the intensive care unit patient experiences of mechanical ventilation. Phenomenology is an inductive research method seeking to describe phenomena that occur as part of human experience.

Phenomenology deals with persons as holistic beings and is congruent with nursing's holistic approach. A clearer understanding of the experience of mechanical ventilation can help nurses deliver more timely, holistic care to ventilator patients who cannot otherwise express their perceived needs. Nurses will be able to develop care plans which take into account the unique needs of ventilator patients.

Setting

The setting for the proposed study was a 600 bed acute care not-for-profit community hospital located in a large metropolitan city in the South Central United States. The hospital is the largest in a not-for-profit healthcare system composed of seven acute care hospitals and three specialty hospitals. It is associated with family practice residents of a medical school, and serves as a clinical teaching site for students in all health care and health care related fields. It is well established within the community, and offers primary, secondary, and tertiary care services.

The hospital houses five eight-room adult critical care units and one step-down unit associated with the intensive care units. Three of the critical care units have the capability of supporting multiple mechanically ventilated patients so those units were

considered for this study. The number of mechanically ventilated patients admitted to those units, including intubations for surgical procedures, total 2000 per year.

All critical care units are staffed primarily with registered nurses and respiratory therapists. Each unit has a central work area for charting, consult, viewing of X-rays, and monitoring patient care devices. Staff can observe each patient from the work area. Work areas can become crowded and noisy, so written reminders are prominently displayed throughout the units in an effort to decrease the noise level which may disturb the patients.

The critical care units have individual patient rooms with sliding glass doors and curtains which can be drawn. The multiple patient care monitors in the rooms have low volume or no volume, so they provided minimal distraction during the data collection period. The step down unit has individual patient rooms with doors which were closed to provide privacy and minimize distractions.

Two general medical intensive care units house the ventilator dependent cardiac, respiratory, gastrointestinal, and neurological patients. If possible there is one registered nurse to care for every patient. The connecting hallway for these units has a room for infectious disease or isolation patients. Occasionally the units for non-ventilator dependent patients are closed for census reasons, and the four units will combine patients and staff for cost-effectiveness.

The medical intensive care units stand adjacent to each other, and they share a common waiting room. Visiting hours are at 10:00 a.m., 12:00 noon, 4:00 p.m., and 8:00

p.m., and last for 15 minutes each visit. No more than two visitors at a time may come to one patient.

The cardiovascular surgical intensive care unit is separated from the medical units. Unlike the medical units, this recently built unit has windows in each patient room. There is a central workstation from which the staff may observe each patient through the individual glass doors. Staff to patient ratio is one registered nurse for every patient.

This unit shares a waiting room with the in-patient surgery. The waiting room is always open. During the day a hospital volunteer serves those in the waiting room and acts as a liaison between visitors and staff. Physicians and other medical personnel enter the waiting room often to offer updates on surgical patients. A support group meeting is held once a week in this waiting room for family of any critical care patient. The visiting hours are the same for the surgical unit as for the medical units, and no more than one guest may visit a patient at the same time.

Population and Sample

The population for study was patients on a mechanical ventilator in a critical care unit during the current hospitalization. Patients eligible to participate were at least 18 years old and had the ability to speak English. Other eligibility criteria were memory of the experience of being mechanically ventilated, willingness to talk about the experience while being audiotaped, and extubation within 72 hours prior to study participation.

Selected clients who had been mechanically ventilated were asked to participate in

the study. A volunteer or solicited sample was used since the potential participants were not known to the researcher. The staff of the participating units were given a letter to orient them to the study and assure them that there were no evaluative consequences related to the study. Included within the letter was a number at which the researcher can be reached.

Staff informed the researcher as patients meeting the eligibility criteria were extubated, and the researcher visited the patients. During the visit, the patients were informed of the study. Potential participants who were deemed “good informants” were asked to participate and data collection proceeded. Morse (1991) describes “good” informants as those who are able to verbally relate an experience after examination and reflection on the situation. Each potential participant was judged on this quality during the interview.

Sampling continued until redundancy occurred and no new information was gained. Redundancy, repetition of statements within the phenomena of the experience of mechanical ventilation, indicated that no new themes emerged from the data (Parse, Coyne, & Smith, 1985). Redundancy confirmed findings rather than contributing new information regarding the experience. A similar term, saturation, refers to repetition of discovered information and confirmation of previously collected data (Streubert, & Carpenter, 1995). Though qualitative studies have no predetermined sample size, review of literature indicated that a sample range of eight to twelve patients was sufficient.

Protection of Human Subjects

This study underwent review by the Institutional Review Board of the participating hospital (Appendix A), and gained exempt review status from the Human Subjects Review Committee of Texas Woman's University. Potential risks to the participants included fatigue, and possible distress from the memory of the experience of mechanical ventilation.

Measures were taken to assure participant rights and confidentiality. Participants were asked to sign the consent form (Appendix B), indicating agreement to participate in the study. Participants were given a code number which appeared on the data collection materials such as the demographic instrument and interview guide, the audio tapes, and the transcripts of those audio tapes. Participant names appeared only on the consent forms. Reported data appeared only in groups. Direct patient quotes appeared in the report, but the participant quoted was not identified. Completed instruments, audio tapes, and transcripts were kept in a locked box separate from the signed consent forms. If participants became distressed by the memories of the experience, they had the right to terminate the interview or withdraw from the study at any time without penalty or prejudice. The researcher offered participants experiencing any extreme distress the opportunity for referral to appropriate resources within the hospital.

Instruments

Instruments used for this were the Demographic Sheet and the Participant Interview Guide (Appendix C). The Demographic Sheet designed by the investigator for

this study was completed using information from the patient's chart or by patient verbalization. The Demographic Sheet was used to gather information regarding the patient's age, gender, race, ICU unit of admission, length of time on the ventilator, length of time since extubation, number of previous experiences with mechanical ventilation, diagnosis and/or reason for intubation/ventilation, patient's understanding of the reasons for this intubation, and medications. The demographic data were used to describe the sample and to determine factors which may have prevented that participant from being a good informant. The patient's understanding of the reason for the current intubation gave insight into the patient's understanding of the situational context of mechanical ventilation. This information, given in the patient's own words, provided useful insight for analysis of the data.

The researcher began the interview of each participant using the following open-ended question: 1) Please tell me about a typical day on a ventilator (respirator). Additional interview questions included: 2) Please describe your thoughts while you were on the ventilator; 3) Please describe how you passed the time while you were on the ventilator; 4) What were your reactions while you were on the ventilator?; and 5) To help me describe the experience of being on a ventilator, what else can you tell me?

The participant's description of the experience guided further questioning by the researcher. Additional probes included such phrases as, "please tell me more about that".

The purpose of the probes was to validate the participant's description of the ventilator

experience and to verify the perceptions of the researcher. The researcher avoided participating in the responses as much as possible to reduce the risk of introducing new ideas or bias into the participant's comments.

These findings lead to a description of the experience of mechanical ventilation as provided by the sample interviewed. They cannot be generalized because individual experiences vary based on life circumstances, reason for mechanical ventilation, and perception of the experience.

Reliability and validity in qualitative research take the form of rigor and trustworthiness. Rigor is demonstrated through the researcher's discovery and confirmation of information. Rigor is intended to ensure accurate representation of the participant's experience (Streubert & Carpenter, 1995). Rigor is supported by the operational techniques of credibility, dependability, confirmability, and transferability.

Credibility includes the activities increasing the probability that the credible findings will be produced, such as returning to participants to see if they recognize and can verify the description of the experience. Dependability is met by demonstrating credibility of the findings. There can be no dependability without credibility (Streubert & Carpenter, 1995). Confirmability is the process by which the researcher documents and illustrates the thought processes leading to study conclusions. Confirmability involves the use of an audit trail or recording of researcher activities which over time can be followed by another researcher. Transferability is the probability that study findings have meaning to others in

like situations. Transferability is determined by the potential user of the findings and not by the researcher (Streubert & Carpenter, 1995). To support the rigor of this study, some study participants were asked to read and verify the description of the experience of mechanical ventilation which was drawn from analysis of the interviews. Trustworthiness was established by accurately representing all aspects of the participants' experiences, including positive and negative situations.

Data Collection

Data collection proceeded upon receiving approval from the Institutional Review Board of the study agency and exempt review status from Texas Woman's University. Data were collected in two of the intensive care units, one medical intensive care unit and the surgical intensive care unit. The units involved received copies of the inclusion criteria to post in the staff lounge and on the unit bulletin boards, and a phone number at which the investigator could be reached.

The investigator maintained contact with participating units to determine availability of potential study participants based on plans to extubate. The participant interviews were conducted within 72 hours of extubation. The time frame allowed the investigator to become aware of and initiate data collection with every possible participant within the study agency. The investigator visited the involved units daily to maintain contact and gain accurate information regarding potential participants. Once a potential study participant was identified, the investigator made contact with the individual,

explained the study, and invited participation. The potential participant had the right to decline without penalty. If agreeing to join the study, the participant was given the consent form to sign giving permission to join the study.

The investigator gave the participant a copy of the signed consent form and placed a copy of the signed consent form on the participant's chart. After placing the copy in the chart, the investigator obtained demographic information from the chart such as diagnosis and current medications. The investigator then alerted the staff to the initiation of the data collection procedure to avoid staff interruptions of the interview process.

The investigator checked the functioning of the audiotape recorder, turned it on, and indicated its use to the participant. When the data collection began, the participant had the opportunity to verbally and in detail express their feelings, thoughts, and perceptions regarding the experience of mechanical ventilation.

Using the questions on the Participant Interview Guide, the investigator asked the participant to describe the experience of mechanical ventilation. The investigator took field notes on the Participant Interview Guide, taking special care to indicate participant body language and mood changes if possible. If the participant became fatigued or distressed from the memory of mechanical ventilation, a rest period was offered.

As the interview proceeded, the investigator reflected the participant's statements back to the participant, or attempted to clarify what the participant was saying. If the participant indicated that the experience of mechanical ventilation had been fully

described, the investigator asked prompting questions to try to stimulate the participant's memory. When the participant indicated that a definite and complete description of the experience had been given, or indicated a desire to stop, the interview terminated.

The participant was instructed that a follow-up interview may occur within 48 hours, the purpose of which would be to verify participant responses requiring clarification during the data analysis period. Likewise, if the participant wished to add to or alter the responses, that participant could contact the investigator to do so. Each tape was given a code number rather than using the participant's name to ensure confidentiality. The duration of each interview was 30 to 60 minutes.

Factors which could contribute to problems with data collection included noise level in the setting, failure of the audio tape recorder, participant fatigue, privacy, or participant distress caused by reliving and describing the experience of mechanical ventilation. Several steps were taken to increase control over these factors. Patients were interviewed in a private room with the curtains drawn or doors closed as appropriate. The audio tape recorder was checked for proper functioning prior to the patient interview. Staff were informed of the data collection so that interruptions were minimized. Participants were given the opportunity to rest as needed during the interview.

Pilot Study

A pilot study was conducted to pretest the instruments, the specified data collection method, and the recall of participants' extubated within 72 hours prior to data

collection. No problems were identified with the instruments or with data collection.

Treatment of Data

Spiegelberg's (1976) method was used for data analysis. Data collection involved field notes and in-depth audiotaped interviews during which each participant was asked to describe the experience of mechanical ventilation. Because of the patients' medical acuity and communication barriers inherent to mechanical ventilation, patients could not provide their perceptions until after extubation.

Each participant interview was tape recorded, and each recording was transcribed by the primary investigator. Each transcript, along with tape recordings and the notes of the primary investigator, was subject to analysis guided by the essentials of the phenomenological method described by Spiegelberg (1976). Essentials are meant to guide the qualitative researcher rather than impose strict structure or impede researcher creativity. Analysis included searching the data for recurring themes and clusters, bracketing preconceived ideas regarding the experience of mechanical ventilation, coding, and grouping the coded data into categories or theme clusters. Data collection and data analysis occurred simultaneously.

Qualitative research begins with no a priori hypothesis regarding the phenomenon or the experiences to be studied. Phenomenological method is based on thought and intuiting and involves logical insight into the sample. Intuiting involves familiarity with the data. Dwelling with the data, reading and rereading the interview transcripts, and

contemplating the meanings hidden within the words of the transcripts will assist the primary investigator in learning and describing the experience of mechanical ventilation.

Spiegelberg (1976) outlined the following seven essentials of the phenomenological method:

1. Investigating particular phenomena;
2. Investigating general essences;
3. Apprehending essential relationships among essences;
4. Watching modes of appearing;
5. Watching the constitution of phenomena in consciousness;
6. Suspending belief in the existence of the phenomena (bracketing);
7. Interpreting the meaning of the phenomena.

The first essential, *investigating particular phenomenon* involves three distinctive but intimately related operations: intuiting, analyzing, and describing. These operations are more commonly referred to as “phenomenological description” (Spiegelberg, 1976).

Intuiting requires complete concentration on the descriptions to allow the researcher to grasp the essences of the experience. Intuiting will be accomplished by reading and rereading the interview transcripts, while keeping the senses open to the implicit and explicit meanings within the participant responses.

Analyzing, the second operation in investigating, is the general examination of the structure of the phenomena according to their components and configuration

(Spiegelberg, 1976). It is the analysis of the phenomena, not the analysis of expressions which refer to them. Analysis is the exploration of the determining characteristics of the phenomena and their similarities, differences, connections, and relationships to other phenomena.

The third operation in investigating is describing, which is an integral part of intuiting and analyzing. Description occurs in conjunction with intuiting and analyzing but cannot occur prior to those operations. Describing is affirming a connection between a phenomenon and all others as it aims to serve as a reliable guide to the listener's or reader's actual or potential experience of the phenomenon (Spiegelberg, 1976). The process of investigating using the three operations of intuiting, analyzing, and describing bring together and elaborate on the elements and structure of the participant's lived experience, and promotes the phenomenological analysis of the experience of mechanical ventilation.

The second essential, *investigating general essences*, occurs by examining the particulars of the participant's experience and by reflecting on their remembered experiences. This essential will be accomplished by continuing to dwell with the data, including the tape recordings, the transcripts of those recordings, and the notes taken by the primary investigator during the interview. The investigator's notes will give insight into the voice inflections and possible mood changes noted on the tape recordings, and may assist in developing the description of the experience. Spiegelberg (1976) stated that

adequate intuiting of general essences can not occur without the antecedent or simultaneous intuiting of the particulars.

The third essential of Spiegelberg's (1976) steps is *apprehending essential relationships*, which involves imaginative variation. Imaginative variation includes omission of certain components within each essence of the phenomenon and replacing certain components with others. Spiegelberg (1976) gave the example of color and extension. One cannot think of color without thinking of extension of the color into space. However, one can think of extension without color, because extension can be transparent. This essential will be accomplished with the coding and categorizing concepts and categories.

Spiegelberg's (1976) fourth essential is *watching for modes of appearing*, and is the systematic exploration of the phenomenon in the sense of what appears, but in the way things appear. Phenomena are not always as they appear, and particulars or essences of an experience will not be known nor adequately described unless they are examined from other perspectives. Spiegelberg (1976) gave the example of a cube, and the fact that one may view the cube from one face or perspective. That singular view will yield a limited description and understanding of the cube. If, however, the cube is examined from many perspectives, the examiner will develop a more complete description.

The fifth essential is *exploring the constitution of phenomena in consciousness*. It is a process of integrating the unfamiliar with the familiar (Spiegelberg, 1976), and is

compared to becoming accustomed to a strange hotel room or forming an impression of a new acquaintance's personality. The investigator develops a level of comfort with the integration of the essence of the experience as familiarity with the data increases.

The sixth essential, *suspending belief in existence of the phenomena* occurs before beginning and is maintained throughout the interviews and the analysis of data. The researcher must recognize and "bracket" self-preconceptions of the experience to be investigated, and set them aside. This researcher has no personal knowledge of the experience of mechanical ventilation, but has developed hearsay bias regarding the experience. To maintain the purity of the data, phenomenological reduction or suspending previous knowledge through bracketing is necessary (Spiegelberg, 1976).

Essential seven, *interpreting concealed meanings* of phenomena is going beyond what is seen in the data to what is believed to be its underlying or unconscious meaning. It is looking for deeper and hidden meanings wherever conscious meanings do not account for a phenomenon and for the total pattern in which it occurs (Spiegelberg, 1976). These seven steps or essentials lead to the identification of structural descriptions of a phenomenon.

Summary

The purpose of this study was to develop a description of the experience of mechanical ventilation. Study participants were over 18 years of age; spoke English; were willing to discuss the experience of mechanical ventilation while being audiotaped; and

were within 72 hours of extubation. The interviews were audiotaped and transcribed by the primary investigator. Descriptions were analyzed using Spiegelberg's (1976) essentials of inductive data analysis.

inhalation and was made aware of the ventilator potential a few months before the occurrence. The second participant was a trauma victim who learned of the intubation from the paramedic. The third and fourth were told of the ventilator before having surgery.

Since this (chemical inhalation) happened, I've had to go to the emergency room a few times. And it's always been in the back of my mind that it could happen where I end up being intubated. In the back of my mind I always knew that was a possibility. And I was scared. I mean I was scared, it's scary.

(Was intubated) cause they shot me right from the back. And there was blood inside my system and they (paramedics) were afraid if blood were in my lungs, and they would be sure that I would be breathing easier and were going to stick this tube in me, I don't know how to describe it. It's pretty dangerous and I had a bullet hole there, and they put me on this bag so I could breathe slowly so I can breathe better.

Going in I had a horror of knowing I was going to be on one of those ventilators. It was just the idea, I guess I always thought if you go on one of those, it's the only thing in the world keeping you alive, and it might be. But the young man who explained it to me was very thorough, and he made me feel like it wouldn't be such a horrible and dangerous thing to do.

Dr. _____ told me I would experience some of this stuff.

Lost Power

The first recognition of actual intubation, whether they were awake during intubation or woke up after surgery and felt the endotracheal tube defined the time of lost power. Lost power occurred anytime during the experience when the participants had difficulty maintaining connections with their spiritual resources, the ventilator, other persons, or had feelings of being victimized. During this phase, patients struggled to reclaim breathing patterns, self-extubate, try to communicate, and try to

move. It was a period of intense fear and feelings of isolation. Patients were disoriented and unprepared for what has happened. They fought or “bucked” the ventilator, as they attempted independence, wanting answers to the questions they could not verbalize. They felt alone, and wanted staff to understand their situation. Fear, aloneness, and feeling victimized characterize lost power.

Lost Power: Fear

Ventilator patients’ initial reaction to intubation or mechanical ventilation was fear. Patients may have known about the possibility of the ventilator and may have been taught prior to intubation, but they were unprepared for the actual experience. This fear, a descriptive element of lost power, included the unknown or lack of preparation and disorientation, and was manifested by feelings of choking or suffocating and struggling against the ventilator.

Fear increased the respirator's rate but decreased depth, which caused the patient’s breathing patterns to get “out of sync” or be opposite the ventilator’s patterns. The feeling of opposition increased patient fear, which caused more rapid and shallow breathing. Ventilator alarms alert the staff to possible life-threatening breathing obstructions, and the noise of the alarms frightens the patient more. Matching breathing patterns or getting “in sync” with the ventilator stops that cycle of mis-matched breathing. The following exemplars illustrate fear.

I remember in the emergency room, they told me they said, "Well, she's going out on us." And I came back, and I was nearly out of it. And then things started to happen. And the next thing I knew they were giving me medicine, and I don't remember anything after that. I woke up down there in the emergency room, and I was paralyzed, it was weird. Cause it was like I could

hear and see everything, but couldn't even move my eyelids. It was the most bizarre feeling I've ever had. It was like my mind was clear and everything but I couldn't move and I couldn't talk at all and that was kind of scary. It was something I was not at all prepared for. Even more than the tube was the feeling of being paralyzed.....So the tube though, at first they had it down way too far, and they had to pull it up a little bit, and I felt like I was smothering still.... I don't know if I was fighting the ventilator, or, it was just hard to breathe. Cause you're restrained, and you keep going up (puts hands to mouth) and you got something stuck here. But I realize the first thing I did was go for my mouth.

I found out about this when they rammed that tube down my throat.

When I woke up from my sleep, I had to have an operation, I felt like I was choking...If I panic, the more I panic, you can hear the alarm, an alarm goes off that tells them something is going on.

I had this machine on me when I woke up. My wife was here and she told me that I had a heart attack and I was (at home) and they Lifeflighted me here. I didn't know I was in the hospital.

Lost Power: Aloneness

Patients struggling with the ventilator or trying to match its breathing patterns experienced a sense of loneliness and isolation. They were becoming accustomed to the idea that the endotracheal tube prevented them from communicating, and they were afraid of what was happening to them at the time. Patients felt a great need to communicate, but were unable to do so. They were often unaware of others in the room, and believed they were alone. They wanted someone to attempt to communicate with them but were frustrated by restrained hands, difficulty in handwriting, and impossibility of sign language. Patients expressed feelings of being the only person who understood their needs and that no others could understand. They felt loneliness, isolation, and a sense of need, and the communication struggles

heightened those feelings. Aloneness, an element of lost power, caused them to focus on themselves.

The following exemplars illustrate the isolation, loneliness, need, difficult communication, restrictions, and self-focus. Participants tried to communicate a specific need to the staff but were unable to do so because of endotracheal tube placement. Each described feelings of aloneness which were heightened by communication difficulties, and therefore increased their sense of isolation and need. Their sense of isolation promoted self-focus as they wondered if their needs would be met. The greater the self-focus, the more intense the need. As their needs grew more intense their ability to connect with their spiritual resources, with the ventilator, or with the staff became more difficult. Lack of connection increased the self-focus, which again intensified the need, and contributed to the extreme negative nature of the ventilator experience. The four exemplars which follow describe the element of aloneness:

I was trying to convey information to them and they acted like they were concerned with only one thing, following the doctor's orders.... They came in and played with the machines and nothing else. They would ask me questions then I would be able to motion "yes" and they understand that. But for the most part they didn't understand what I was trying to tell them. It was difficult for me to let them know that I needed certain things done. They needed to ask me questions pertaining to the situation. They were asking me the wrong questions.... And they keep asking the wrong questions, and here I am, I have to answer a question so that I could get into a situation where I could communicate with them. The only thing was I didn't want to say "yes" to one of their questions unless that was the answer. They would say, "Are you in pain?" Well certainly I was in pain but that wasn't the message I was trying to give them. I was trying to communicate that they were asking the wrong question. That would get them off track... they would be thinking they had solved the problem but they hadn't.

Being able to need something and not having a pen to write with. I think that's the first thing they should do, when a person is coming out of it is for them to have a pencil there for you to communicate.

It was hard (not to talk) because I was in pain and nobody understood me. I wanted them to understand that I needed help.

You can't talk, and my arms were tied for several days. So I had about this much give (approximately 4 inches). So whatever I needed, sometimes they would untie my arm so I could try to write. Other than that I couldn't communicate except by trying to point.... I have one bad tooth and every time I would try to move (the tube) while I was on the ventilator someone would say, "Oh no, no, no, no, don't try to take the tube out of your mouth!" Well I couldn't tell them what I was trying to do.

These participants described pain, but important to note is that this was not pain directly related to the presence of the endotracheal tube. The first participant was complaining of incisional pain, and the third complained of pain related to trauma. The participant wanting to reposition the endotracheal tube did so because of the pressure and pain on an abscessed tooth. That participant adds:

If I could stress anything it would be that if someone is in a position where they can't communicate, they feel out of control, and they (staff) should be aware of all the physical things. Like I said, I told my brother who was here the other night, I feel like I have a pretty good idea what it would be like to be a POW.

Other participants realized the need to focus on something other than themselves to make the experience less negative. The following exemplars illustrate that realization:

The only thing I felt was, it was just uncomfortable sometimes. You don't even notice that you know so much if you're not just laying there thinking about nothing but yourself.

You can't just stay there and look dumb day in and day out. You gotta have something.... I like short and funny (TV) shows. Humor helps keep your mind off of it.

Lost Power: Victimized

Staff behaviors often caused participants to feel victimized by caregivers. Lack of caregiver compassion or competence as perceived by participants caused feelings of fear, discouragement, mistrust, and hopelessness. Feeling victimized increased their sense of self-focus and their sense of need. Some participants stayed primarily in the lost power phase because of the perception of being victimized, and were able to get in sync with the ventilator only after being exhausted from the struggle and fight. When patients perceived inhumane or uncaring treatment from the staff they felt alone and isolated. They continued to focus on themselves and their unmet needs, and they considered the ventilator experience extremely negative. The following exemplars illustrate lack of patient connection with staff related to patient perception of uncaring treatment:

The physician's assistant said that I had an intestinal obstruction. And it wasn't until I couldn't speak at all, and I was tied down this OB-GYN came in and told me that I had ovarian cancer. He didn't operate on it, but he said that I possibly have six months to live, or I might die in transit to (cancer hospital). They planned on if I lived, sending me there. That to me was the single most horrible experience of my life. Like I said, I couldn't talk, and I couldn't move and there was no one there that I knew, and I was hurting. That kind of pain is worse than physical pain. I mean it's one thing to try to be straight with somebody, but this was cruel.... Looking back over that treatment, it was sometimes just barbaric.

They pay more attention to that thing (points to monitor). They're paying attention to the bing, bang, bang, and that would drive a person wacko. Cause I've seen them come in and move away and they're not even looking at me. I'm limited in my movement because at that point in time I was hurting so bad and I hadn't received any pain medication. I would get frustrated and that would make it worse.... They didn't understand that because they can't feel my pain.

Some participants described times when they perceived staff members as less than competent. Perceived lack of competence left participants mistrustful of staff. These descriptions were associated with perceived lack of compassion or lack of communication. Exemplars following describe the participants' perception regarding lack of competence.

Now I went several days without my mouth being washed, and finally a nurse came in and wiped my mouth. I said, "Hand me my pad", and I sat and wrote her a note, "____, you are the only one who will wipe my mouth for me, because the others, none of them cared enough and they would just leave me". And she said she was sorry to hear that, then she tore up the note. But maybe by telling somebody now it will make it okay.

(They should have asked) if I was thirsty. But they asked every other kind of question there was. One of them did ask if I was thirsty. And you would think they would remember that next time but they didn't. Every time I had to go through the same thing. It was very difficult for them to understand. It was frustrating. It was so painful to go through.....It made it difficult for somebody to come in while I'm trying to talk to this lady, and here's somebody else come in they got to take your blood pressure or whatever. Normally that wouldn't bother me at all but at the time it did because it interrupted something I was having a great deal of difficulty trying to communicate. I couldn't even talk, I couldn't voice anything and say, "Wait, wait, wait, wait!" I would make signs and they didn't know what I was talking about so they would just kind of ignore me. They didn't get the message so it was kind of difficult.

Hopelessness was evident when patients faced frequent fear and discouragement. The following exemplar is from a woman who felt victimized by the staff, so displayed little courage, no trust, and little hope.

Well, it's degrading... You're just at the mercy of them. It's an experience I wouldn't wish on anyone....It was just like torture...the treatment was sometimes just barbaric. I decided that I would rather die than have that thing in my mouth.

In Sync

Patients must have the courage to surrender their own natural breathing to the predetermined rate of the ventilator. Only then will they be able to feel less fear in the situation. Patients connect with their inner resource of courage to be empowered to surrender their breathing to regain partial control of the situation by helping establish trust in the ventilator and in the staff. Surrendering control of their own breathing patterns to connect with a machine can be dehumanizing and frightening, but that connection is required to establish the trust necessary for survival.

When patients are able to surrender to the circumstances and the ventilator, they cease the struggle, shifting from lost power to in sync. They move from fighting to accepting the situation. Patients learn ways to adapt so that the experience is less negative. To get in sync they must connect with their own spiritual resources of courage, trust, and hope. By getting in sync with the ventilator, they gain the courage needed to trust life-saving technology and staff and hope for the life after the ventilator experience. Spiritual resources provide strength to regain power in the situation by accepting and surrendering to the circumstances. Acceptance and surrender enable patients to stop fighting and manage the experience more easily, becoming a partner with the machine.

Time needed to get in sync varies among patients. The lost power phase may be no longer than a few seconds or minutes, at which point patients attempt to get in sync. Achieving and maintaining the sync depends on patients' connections with their resources, with the ventilator, and with others. Disruption in those connections,

which can occur at any time during the ventilator experience, causes patients to again experience lost power. Because in sync is characterized by connections, disconnection characterizes lack of sync. Fear, disorientation, staff behaviors, lack of knowledge or preparedness, or other disruption causing patients to perceive themselves as powerless victims within the circumstances can cause disconnection which results in recurrence of lost power. In sync is characterized by patients' connections with themselves, with the ventilator, and with other persons.

In Sync: Connecting with Self

Many participants discussed ways of coping with the ventilator experience. Some thought about the past or the future, and some thought about relationships. Two participants described relationships with God as their source of strength. Connecting with self and spiritual resources was a likely indication of other connections because self-connection provided the strength needed to make other connections. Lack of self-connection or disconnection rendered the patients more vulnerable and less likely to make other connections. Though the terminology was not used, participants described times of self-transcendence to "remove themselves" and survive the experience. Removing themselves from the experience decreased the times of self-focus. The following exemplars describe participant self-connection and self-transcendence:

Back when I had that tube in me I thought of my mom when she passed away. People that I knew that had passed away that I thought I would never think of in the future. I was thinking about the family.

(I thought about) all kinds of bad stuff, hoping for the good stuff. What I did before here, what I'll do when I get out of here, what's wrong with me, and am I going to get fixed.... Think of good times, like catching that big red snapper that I caught.... And you do a lot more praying when you're in that condition than when you don't need it. I'll tell you I believe in it!

Monday afternoon I was pretty much coherent, and I was sitting up reading a book.... If you can't relax, I don't know how someone could deal with it, I really don't. It would be really hard if you couldn't make yourself relax. It would be real easy to stay panicked.

In Sync: Connecting with the Ventilator

This element describes two aspects of connecting with the ventilator, the mental/emotional synchronous connection and the physical connection from patients to ventilators via endotracheal tube. Courage and trust are required to surrender breathing to a machine, but that surrender is necessary. Participants discussed the need to connect or synchronize their own natural breathing patterns with the ventilators' preset patterns. They discussed the importance of relaxation in the synchronization process, and some discussed ways of achieving and maintaining sync. Some patients were able to overcome their fear and more easily adopt the ventilator's preset patterns. One patient described his experience of matching the breathing patterns and gave advice for future ventilator patients:

Well, you kind of hold your breath until it gives you a puff you know it's kind of hard to do sometimes. But you try to get in sync, you know. The machine really matches your synchronization. So if you keep breathing normal then you start breathing fast, you get out of sync. What you need to do is get back into your original breathing pattern. When a person gets shook up or nervous they start breathing faster.... When you're breathing fast, you're breathing shallow. And you're not getting oxygen into your lungs like it should be... People ought to know that the more you don't fight this thing the easier it's gonna be on them.... And nothing I tell you is going to change much of it. It will still be scary..... Let people hear this, don't get scared! When you get

scared you gotta breathe fast and you feel like you're not getting any air and you feel like you're gonna suffocate. The more you fight it the worse it is.

Connection with the ventilator was sometimes difficult to achieve, and once achieved was difficult to maintain. The following exemplars from three participants describe the experience of disconnection with the ventilator.

I thought I was smothering or suffocating. I was telling them when I needed to be suctioned. I knew when I needed to be suctioned, where they stick that little hose down the tube, and you can't feel it at first, then all of a sudden you start gagging. It must have just passed through the tube and gone into your lungs and start coughing and gagging. It's strange, and it's not real comfortable, but afterwards it makes a big difference... it's easier to breathe.

I think when they tried to take it out I couldn't get in sync with it. It must have been my next breath and the machine missed it again. It picked up the next breath which was good, but it was just that every other breath had oxygen. That's all it was.

And I couldn't sleep, it's hard to sleep, it's hard to concentrate on breathing at the same time because it's a slow breath, extra slow breath you know. But if you go too fast, you're gonna choke.... And it's pretty weird that it just feels different like you're in a box cause you don't hear yourself and breathing like I said it's just slowly breathing. You just keep that beat breathing.

The endotracheal tube was the physical connection of patient to machine.

Some participants believed the presence of the tube was not as important within the experience as were the effects of having the tube. Following are descriptions of the perceptions of intubation, the endotracheal tube and suctioning.

Well that's an experience putting that tube down.. If you're sedated or out of it when they put it down course you don't know it. But when you're awake they put it down you they go so far down your throat and they say, "Swallow hard", and they push it I guess and put that thing up in your nose, and that don't feel so good. ... (Suctioning) is not really all that uncomfortable once you realize what's going on. All they do is put a little saline solution and go down and loosen up all that phlegm and then they tell you to cough and they suction to bring that stuff up in the little plastic bag and it pulls it up so it's better. And you ain't got all that cacklin' noise afterward. It's uncomfortable,

but if you know it's only gonna last this long (snaps fingers) a few seconds is okay.

I just remember that I was very sensitive to it... I'm a very gaggy person, you know, that was all down in my throat. It was bothersome.

I was more aware of the tube than uncomfortable.

In Sync: Connection with Others

Human relationships are of extreme importance during the ventilator experience when patients are surrounded by and physically attached to various machines and instruments. The potential for being regarded as part of the technology instead of as a holistic human being is very high. Patients are vulnerable and are striving to maintain their identity as persons. Connections with staff, with significant others, and with other patients help them maintain their identity as persons surrounded by technology instead of as an attachment to the technology.

Patients require compassionate treatment by staff and others to maintain connections with themselves and the ventilator. Treatment perceived by patients as uncaring or unfeeling can cause them to disconnect from their spiritual resources, especially trust, which may have been broken by the encounter. If patients cannot trust the staff to provide humane, compassionate care to meet their needs, they return to the feelings of isolation, loneliness, victimization, and self-focus perceived during the lost power phase of the experience. The three exemplars that follow illustrate connection with staff:

The nurses were very patient with me. Everyone was very professional.

And this nurse was always there watching me, mostly 15 to 20 minutes, and every time I needed her she was always looking at me, and if I had a problem, the rest of the people who had a problem in bed, she was watching them, too And the nurses treated me pretty good by telling me what to do, and they were telling me that everything was all right and okay and that nothing was going to happen. "You'll be all right." They'd be there holding your hand for support, and they'd just be there.

Well when you come out from the bypass surgery you have a nurse with you all the time. She was right there with me, and really she was very attentive to me, and helpful as anyone could be.

Competent care was just as important as compassionate care. Participants felt connections with staff based on the trust established by providing competent care. Exemplars that follow illustrate these connections. The first participant claimed little memory of the experience, yet mentioned a specific nurse by name. The specified nurse cared for him only while he was on the ventilator. The second and third participants experienced the mechanical ventilator in open concept units with multiple patients in a ward, and both recalled watching staff interactions while awake.

___ was very good. She was very proficient and she made it easier for me.

They were all very nice. Everybody up here. They just did their job like I was their kid or something. They took care of me. They all seemed real concerned about their job. I do know these are some good folks here. Ain't nobody need for nothing, they all treat you good. Nobody mean. Anytime you need something they were there for you.

They (staff) were never confused, or if some people were confused they would talk to each other to solve their problems. That's why I was watching and listening. They were over there like, "No you can do it this way, but it might be easier the other way around." And they would work it out, they would just work it out. They helped each other to solve problems.

Relationships were very important to patients during the ventilator experience. Visitors gave them a sense of hope and often provided the strength needed to manage

the experience. No participant discussed visitors as negative, and each mention of visitors was described as making the overall experience easier to bear. Below are exemplars describing the importance of visitors.

They're praying for me now. It helps tremendously to know that because I know God answers prayer. And there's been people calling on me that I never expected. It's amazing. And that's increased my faith. The fact that these people are calling or coming to see me. My son knows the pastor at the church that I was born and raised in.... This one particular man I had never met but he's the pastor of the church now where I grew up. I used to go to that church when there was another pastor. But here's this guy (pastor) sitting outside, and he was the last person I expected to see here. To me that means that God was out there, and that God is looking out for me. That's what brought me through it I believe.

I was fortunate in that I did have family and friends come in and that helped. If I had been on my own, I don't think I could honestly have lived through the experience.

My parents came as visitors and my brother. And I had my tube in me. And they see me like I'm having trouble cause they would keep holding my hand. It's like they knew what I was thinking. Like I was having trouble, but they couldn't do nothing about it. Even my brother had to hold me down like "It's alright, it's alright". I know how they were thinking, that I was having trouble.

Some participants spoke of being aware of other ventilator patients.

Awareness of other patients was not described negatively, rather as a source of strength as they realized they were not alone in their circumstances.

I would see other people sometime I could see that one of them would have the same thing. I could barely hear when they were flushing their system that it was not as loud as mine cause I could hear it more cause it was me. Theirs was different, a light sound, you can't hear it. When they're flushing other persons you can't hear it.

I could hear other people's conversations but that didn't faze me.

I could compare it (nasal intubation) to pumping my stomach. It didn't bother me too much, but I heard other people griping about it.

I liked knowing they were taking care of everybody, not just me.

Life After

Patients began to move to the life after phase as they became accustomed to the ventilator and its patterns, because they used less energy bucking the ventilator and were able to concentrate on the future. Potential for movement to lost power and in sync phases still existed, but patients began to realize the ventilator experience would be over eventually. They experienced relief and started to put the experience in perspective. In addition to the relief, some patients considered the life after phase a time of anxiety and dread as they considered the possible inability to reclaim their own natural breathing patterns. Spiritual resource connection was important in this phase because patients drew on their own courage to give up the life-saving and life-sustaining mechanical ventilator, trusted that they would be able to breathe spontaneously and independently, and trusted others to care for them if they did not breathe on their own. It was a time of hope as patients realized that the end of the experience was near.

After extubation they exhibited physical symptoms associated with intubation, and some of those symptoms played prominently within the entire experience. Often patients would express gratitude for the life-saving technology and caregivers. Elements descriptive of life after are relief, physical discomfort, and gratitude.

Life After: Relief

Participants expressed relief at the news of impending extubation. The following four exemplars describe the relief.

I was just glad to be off it.

I had a great deal of relief.

Great! You can move your head without it hurting.

Very good. My mouth was getting dry and I needed water.

In addition to relief was the feeling of dread associated with extubation.

Participants did not know what to expect, and there was uncertainty regarding their own breathing. Descriptions of dread follow:

Knowing it was there, didn't bother me to know it was there cause I knew I was still breathing. I dreaded the thoughts of it coming out, thinking it would bother me. I thought it would hurt, or what if I didn't breathe on my own?

When they took out one tube at a time it was real uncomfortable because it felt they were all coming out of my mouth and they sucking up all the mucous in my nose.

But see the problem I encountered was that if I insured them that I could breathe on my own then they take (the tube) out. But they weren't about to take this tube out of my mouth until I could breathe on my own.

They leave it in for a while without the help of the ventilator in case you can't handle it on your own. They're not going to pull the tube out until they're sure you can breathe on your own.... They're not going to pull the tube if you can't breathe, then they'd have to put it back down. That is no good.

Physical Discomforts

Discomforts with extubation or post-extubation physical discomfort were so prominent within the experience that they were often among the first details,

mentioned. The following excerpts describe the extubation or post-extubation discomforts:

It hurt little. It didn't feel at all like I was expecting it to feel. It was like, take a deep breath and it was over with you know. But it kind of surprises you. It's just a strange feeling. So that sat me up, all the way up and they said, "We're gonna undo the ventilator and the balloon. We're gonna have you draw a breath, and it'll be out." So they like pulled it and it was done before you knew what was going on. Then my throat was really sore.

They were pretty strict on the diet. Cause after that machine, you know, it hurts your throat. Right when they take the whole thing out you gotta cough it out. Your throat is sore for two or three days. It's hard to drink water, and it's even harder to eat food cause I try to eat candy that I have, and I couldn't eat the candy. I had to spit it out. But the water's there...little sip, sip, sip, sip.

Well, it's real hard. It makes you sore. You know it's up in there and your mouth is watering all the time. I have to use this suction pump right here (Yankauer suction catheter).

Life After: Gratitude

Participants did not display gratitude for the mechanical ventilation experience, but for the technology and people who kept them alive. They acknowledged the importance of the ventilator and the staff in their recovery. Though the language may have been different, their acknowledgment indicated gratitude. The following exemplify the participants' gratitude:

It's a miracle I'm even alive. I have so many problems.... But I know this has to come from God giving me strength where I didn't have it. He helped me overcome the problem and I'm grateful to Him for that.

Well, you know that (the ventilator) really and truly never bothered me. Cause when I woke up I realized I was alive (chuckles) and I never thought about it and that's a fact.

My family thinks I was treated very nice.

Additional Findings

One participant from the current study had experienced mechanical ventilation two times within a six-month period in two different settings. That participant described the first experience in a severely negative manner, but described the current experience in a more positive and hopeful fashion. The exemplar that follows describes the first ventilator experience. These data were not included within the study analysis because the six-month time frame was inconsistent with the protocol of this research.

The first time was awful. I came out from being sedated for several days, and I'd try to use sign language with them, but most of them didn't want to know what I was trying to say. It was very hard. That first experience was hell. I was scared to death because when I come to I was tied, and I thought I had a bowel movement and I was still groggy and I would kick the bed. Someone would come in and would point here (mid body), and I'd make sign language and they'd say, "I don't understand" and walk away. And I'd start kicking the bed. In other words, I didn't have a very sensitive person at all taking care of me.... It made it worse that they weren't sensitive to my needs. If they'd told me I had a diaper on or whatever and not to worry about it, that's private to me, you know. I don't much care for a bedpan, I want to get up and go to the bathroom. But you can't. But anyhow, I'm not sure, I was still groggy, but I think that whoever that was slapped me. If I could recognize him.... I was still groggy; it's just that first experience was pretty bad.

During the first experience this participant entered the lost power phase after awakening from surgery. He had little knowledge of what to expect from the experience, and received little compassion or communication from the staff. He perceived himself a victim of the staff and the ventilator because he was scared, uninformed, unable to communicate, and unable to have his needs met. He felt isolated and alone, and could do nothing but focus on himself as he struggled to match his own breathing patterns to the ventilator's patterns. He fought with the

ventilator and the staff until he was extubated. Though he was able to match his breathing patterns, he was not able to experience the trust and hope that come with thinking about life before and life after the ventilator experience.

During the current experience this participant discussed getting in sync, communicating with the staff, compassionate care, and hope for the future. He defined the major difference in the experiences as having a caregiver who was more sensitive to his needs. He also discussed the importance of prior knowledge of the experience:

The thing ought to be explained a little better before you go on I think, especially if you never had it before.

Summary of Findings

Analysis of the interview transcripts from the 11 intensive care patients yielded phases within the phenomenon of the experience of mechanical ventilation. Contemplation of the categories and their descriptive elements led the researcher to the following summary description of the phenomenon:

The intensive care patients' experience of mechanical ventilation is a time of drawing on internal spiritual resources they had utilized in their life before the experience in order to cope with their perceptions of lost power, as they strive to stay in sync with the ventilator and other persons, and as they look forward to life after the ventilator experience.

Connection with spiritual resources of courage, trust, and hope was identified as the core phase upon which the phenomenon was based. Connection with their own

spiritual resources gave them courage as they worked toward connecting with the ventilator to synchronize breathing and trust and hope that it would continue to keep them alive, and as they worked to connect with other persons, trusting them to provide for the physical, emotional, and spiritual needs they could not meet independently. Spiritual resource connection helped them maintain their identities apart from the ventilator instead of being lost in a maze of tubing and technology.

Patients entered the context of mechanical ventilation with perspective, relationships, knowledge, and power that identified them in their life before the ventilator experience. Their life before mechanical ventilation held their identity by giving assurance of patients' prior independence, decision-making ability, and contribution to society. The spiritual resources patients used to manage the stressors and challenges of life before the ventilator provided the source of strength required to manage the challenge and stress of the ventilator.

Patients struggled to regain their personal power as they realized they were intubated and had lost power. They struggled with the ventilator as they tried to reclaim their own breathing patterns, and they were disoriented and afraid of the ventilator, the immobility, and the lost communication. They felt isolated and alone, and began to focus on themselves and their needs. They wanted to communicate their fears and needs to others, but because of the associated difficulties were unable to make their fears and needs known. As patients became aware of the nature of their circumstances, they realized the importance of relaxing and ending the struggle by surrendering their breathing patterns to the ventilator.

Courage and trust were needed for patients to surrender their natural breathing to a machine in order to get in sync with it and with other persons. As they attempted to maintain synchronized breathing, they attempted to trust that the machine would continue to sustain their lives and that others would care for them. They thought about the times before the ventilator experience and began to hope for the time after the experience. Patients participated in their previous coping strategies as much as possible within the context including self-transcendence and prayer. Courage, trust, hope, and use of previous coping strategies provided a greater sense of power within the circumstances. Disorientation, staff behaviors, fear, and lack of preparedness threatened patients' connections with their spiritual resources, contributing to their sense of powerless, described as lost power. A dynamic experience throughout, patients could experience in sync and lost power intermittently during ventilation.

When patients became more accustomed to the ventilators' preset patterns, they began to think more about their lives after the ventilator. They experienced a mix of relief and dread at the idea of giving up the machine they had learned to trust. Patients displayed sequela associated with the presence and removal of the endotracheal tube such as sore throat and dry mouth. Despite the physical symptoms, patients described feelings of gratitude toward God, the staff and other persons, and the ventilator for saving their lives.

CHAPTER 5

SUMMARY OF THE STUDY

Mechanical ventilation is critical to the effective management of a patient whose normal breathing pattern has been compromised by chronic or acute medical conditions. Thousands of people with chronic and acute illnesses require intubation and mechanical ventilation each year. Patients receiving ventilator treatment are poorly prepared for the experience, even with the benefit of pre-event teaching. They are not prepared for the loss of control and loss of communication, which strongly characterize the experience. Ventilator patients are concerned with their own survival needs, but are unable to express those needs. They are therefore dependent on nurses to recognize their needs, and to correct problems inherent with mechanical ventilation. The purpose of this study was to explore and describe the phenomenon of the experience of mechanical ventilation as perceived by intensive care unit patients.

Summary

The experience of mechanical ventilation as perceived by intensive care unit patients was explored using the qualitative method of phenomenology. Data were collected from post-extubation, intensive care patients within a large not-for-profit hospital system in the southwestern United States. A purposeful sample of 11 patients participated in the study. Sampling ceased when redundancy in the data was achieved. Participants were interviewed using a semi-structured Participant Interview Guide (Appendix C). Each interview was flexible in order to allow participants to fully explore

perceptions in determining the phenomenon. Interviews were audiotaped and transcribed by the researcher. Each transcript was analyzed using the phenomenological essentials detailed by Spiegelberg (1976). Contemplative dwelling with the data resulted in uncovering of phases descriptive of the phenomenon which were shaped by descriptive elements emerging from further data analysis. Essential relationships between elements within a phase were captured through imaginative variation. Modes of appearing in relationships between categories emerged which resulted in the following description of the phenomenon:

The intensive care patients' experience of mechanical ventilation is a time of drawing on internal spiritual resources they had utilized in their life before the experience in order to cope with their perceptions of lost power, as they strive to stay in sync with the ventilator and other persons, and as they look forward to life after the ventilator experience.

Two informants who had previously experienced mechanical ventilation verbally provided feedback to the working analysis in order to validate the findings. The reviewers confirmed the description of the collective experience as being similar to their own.

Discussion of Findings

The experience of mechanical ventilation is dynamic as it unfolds and moves across and among phases. Participants discussed experience periods of lost power after achieving the in sync phase as they perceived episodes of unpreparedness and lack of caregiver compassion or competence. These events caused participants to perceive

themselves as powerless victims subject to the will and whims of the staff. Perceptions of compassionate and competent caregivers helped participants to achieve and maintain the in sync phase.

During the lost power and in sync phases participants connected with their spiritual resources of courage, trust, and hope to survive the experience. They also drew on past coping strategies such as transcendence and attempted to manage the stress of the ventilator in ways similar to those used in the past. As they connected with their resources, they were better able to stop struggling and synchronize their breathing patterns with the ventilator, and were able to use their energy to make connections with the staff and other persons. Connections with others helped participants maintain their identity as human beings rather than feeling dehumanized as part of the technology. Feelings of being human contributed to participants' perceptions of power within their circumstances.

Participants entered the ventilator experience with their individual perspectives, relationships, knowledge of medical histories, and personal power. During the experience some participants thought about their lives before mechanical ventilation and attempted to put it in perspective. As they put things into perspective they were able to use their courage and trust to surrender to the ventilator by remembering how they had managed the challenges of their lives before the ventilator. Memories of family or other persons gave participants the strength to manage their circumstances, and some expressed the importance of family in their surviving the experience.

Some participants thought about the future and had hope for the time after the ventilator. As they thought about their lives after, they drew on their spiritual resource of hope to help them through the experience. Those staying primarily within the lost power phase due to unpreparedness or perceived staff negative behaviors may not experience the hope for the future that comes with thinking about relationships or the life after phase.

As they prepared for extubation and life after the ventilator experience participants felt relief at the thought of having the tube removed, but they also had some uncertainty regarding their abilities to breathe independently. They had come to trust that the ventilator would continue to breathe for them, and were concerned about reclaiming their own breathing patterns. Participants had to again draw on their courage to breathe without the ventilator, and trust that they would breathe on their own and that staff would care for them if they did not breathe on their own. They also experienced gratitude for the technology and the caregivers who had kept them alive. Some expressed gratitude for their visitors or others from whom they felt support. Participants described discomforts related to the intubation and extubation.

Nineteen mechanically ventilated intensive care unit patients were informed of the current study and invited to participate. Of those, 11 (58%) patients had recall of the critical care experience of mechanical ventilation. This finding was consistent with studies by Bergbom-Engberg, Hallenberg, Wickstrom & Haljamae (1988) and Simpson, Armstrong, & Wilson (1989) which found recall in 50% and 64% of mechanically ventilated patients respectively. In contrast, the study by Green (1996) found that 92% of patients interviewed had recall of the experience.

A major stressor among ventilator patients is lack of communication or inability to communicate with others. All participants within the current study described communication difficulties as a major source of stress. Many discussed the inadequacy of writing notes or attempting sign language to communicate their needs to staff. This finding is consistent with the literature (Parker, Schubert, Shelhamer & Parillo, 1984; Stovsky & Dragonette, 1988; Pennock, Crawshaw, Maher, Price, & Kaplan, 1994; Verity, 1996; Hafsteindorf, 1996; Menzel, 1997). These authors reported that lack of communication was a major source of stress among ventilator patients and that some consistent means of communication was needed.

Participants discussed the need for caregivers who were able to communicate with ventilator patients to be better able to meet patient needs. They also suggested that caregivers provide explanations for every action and procedure to help with communication by promoting orientation and decreasing unpreparedness. Hafsteindorf (1996) and Verity (1996) each found that nurse presence, explanations and use of touch as communication tools were important to patient well being. Stovsky and Dragonett (1988) found that ventilator patients who received prior teaching with a communication picture board considered the board useful during their ventilator experience.

Participants within the current study reported periods of anxiety, fear, isolation, self-focus, mistrust, and discouragement. Most of these feelings were associated with initial realization of intubation and its associated loss of personal power and with perceptions of staff mistreatment. Participants were better able to manage the experience when they could draw on their own courage, trust, and hope to get in sync with the

ventilator patterns and benefit from the care of compassionate and competent nurse. This finding is consistent with a study by Bergbom-Engberg and Haljame (1990) who found that ventilator patients felt more secure when they could synchronize breathing patterns with the ventilator, receive care from an expert nurse, and use their own feelings of hope and faith in God. Riggio, Singer, Hartman, & Sneider (1982) found that anger, anxiety, and frustration in ventilator patients was related to inability to communicate with staff.

In contrast, a study by Wilson (1987) found that psychosocial distress was caused more by noise, time disorientation, and staff discussions. Another contrasting view comes from the study by McCartney and Boland (1994) which found that the root cause of anxiety in mechanically ventilated patients is the response of combined factors such as serious illness, central nervous central disorders, drugs or medications, and medical procedures. Participants of the current study discussed knowledge of medical conditions in the context of personal power from having information. None of the current participants appeared to suffer psychological side effects of medication, and none had history of central nervous system disorder.

Physical symptoms associated with the disease processes, surgeries, intubation, and synchronized breathing were common. Participants discussed incisional pain, discomfort from restricted movement, discomfort related to endotracheal tube placement and difficult communication, and intensified pain or other needs resulting from self-focus. They also described discomfort associated with fighting or “bucking” the ventilator’s preset patterns, and talked about pain associated with extubation. These findings are consistent with writings by Hudelston (1977) and Baier and Schomaker

(1985); and with studies by Jones, Hoggart, Withey, Donaghue, and Ellis (1979); Bergbom-Engberg and Haljame (1989); Turner, Briggs, Springhorn, and Potgieter (1990); and Johnson and Sexton (1990).

Participants within this study offered examples of courage, trust, and hope while mechanically ventilated. According to Stoll (1989), dimensions of spirituality incorporate courage, trust, and hope. Of the 11 interviewed, two discussed faith in God as the source of their strength while nine made no mention of God, a higher power, or religion. Persons must draw on their spiritual resources of courage, trust, and hope to manage the stressors and challenges of daily life (Stoll, 1989). Intensive care unit patients or others exhibiting life-threatening diseases such as cancer rely on those resources as a source of strength (Sodestrom & Martinson, 1987; & Stoll, 1989). Mechanically ventilated patients who are alert but are unable to speak because of the presence of the endotracheal tube between their vocal cords can do little except connect with and utilize their own internal resources. They may reflect on the past and on the future and they may pray for themselves or for others (Baier & Schomaker, 1985).

Ventilator patients describe the importance of humane, compassionate, and competent care in helping them to draw on their spiritual resources by promoting their sense of human relationship and connection. Patients cannot draw on their spiritual resources, especially hope, without the presence of other persons. Human relations and interactions promote the connection and inner harmony needed to better survive the stressors associated with intense life experiences such as that produced by mechanical ventilation (Dickinson, 1975; Sodestrom & Martinson, 1987; Nagai-Jacobson &

Burkhardt, 1989; Stoll, 1989; Clark, Cross, Deane, and Lowry, 1991; Walton, 1996; & Sherwood, 1997). Though this researcher found two references which addressed spirituality in ventilator patients (Baier & Schomaker, 1985; & Bergbom-Engberg & Haljamae, 1987), participants in the current study demonstrated findings specified in literature, including the need for human connections and relationships.

There is a need for patients to connect with themselves and their own spiritual resources of courage, trust, and hope to fully draw on the spiritual nature of their past, present, and future. Nagai-Jacobson and Burkhardt (1989) stated that nurses who understand the importance of self-connection recognize the significance of the patients' past, present, and future and the significance of events, relationships, and experiences in shaping the person's well being and understanding of life. Clark, Cross, Deane, and Lowry (1991) found that the most significant contribution to a patient's sense of well-being and hope was a nurse whom patients trusted to deliver compassionate care which provided a human link between them.

Conclusions and Implications

Mechanically ventilated patients are at risk for feeling dehumanized and alone as their caregivers give needed attention to the life-giving technology. Patients' inability to communicate because of the endotracheal tube causes them to feel alone and isolated. Perceived lack of staff compassion or competence causes patients to feel neglected by their caregivers, which contributes to the feelings of aloneness and isolation. Patients may focus on themselves and their perceived unmet needs. Though these feelings may not be completely eliminated, they can be made less intense by providing holistic care

which attempts to meet patients' physical, emotional, spiritual, and relational needs.

Compassionate care allows patients to connect with their own spiritual resources to better manage the stress and challenge of the ventilator experience. Conclusions and implications for practice reached from the findings of this study include:

1. The experience of mechanical ventilation is changing and dynamic based on patients life before the ventilator, the intensity and duration of feelings associated with perceived loss of power, patients abilities to get in sync with ventilator and other persons, and the ability to think about life after the ventilator event.

Findings indicate that ventilator patients draw on their previous coping strategies including thinking about other persons, prayer, reading, and thinking about their past or their future to manage the experience. Patients not using these resources during the experience have more feelings of lost power and self-focus because they are unable to think about other things. A plan of care should be utilized which encourages patients to remember the past and think toward the future to manage the stress of the ventilator experience.

2. The experience of mechanical ventilation is a time of spiritual need as patients attempt to manage their feelings of aloneness, isolation, and self-focus by connecting with their spiritual resources of courage, trust, and hope.

Findings indicate that mechanically ventilated patients must have the courage and trust to surrender their breathing patterns to the ventilator as they attempt to communicate their needs to staff. Difficulty in communication causes patients to dwell on their unmet needs as they strive to find the best method of making their needs known. Inability to

communicate their needs increases their sense of spiritual need by increasing their aloneness, isolation, and self-focus. Unmet spiritual needs could lead to spiritual distress, which could inhibit the holistic healing process. Patients stated that their spiritual resources were best accessed when caregivers were compassionate and competent. Basic education for nurses should include the effects of care behaviors on the patient's holistic well-being, appropriate referrals to hospital chaplains and other clergy, and regular spiritual assessments. Practicing nurses should strive to establish in patients a sense of trust by delivering timely, compassionate, competent care.

3. Communication difficulties increase patients' perceptions of pain and discomfort.

Patients described instances during which they tried to explain their discomforts, but were frustrated by inadequate communication methods. Many patients voiced the concern that most patients must have similar problems of communicating pain or other needs but became discouraged in the attempt. Some patients stated that nurses should have writing materials available as soon as possible for patient use, and others said that staff should become accustomed to asking patients a wider range of questions related to the ventilator or their physical condition. Many patients face restrictions with physical movement or visual limitations, therefore note writing may not be appropriate. A plan of care should involve the use of touch, simple and direct questioning of patients concerns, and explanations for all patients. Use of picture boards and flash cards designed to enhance communication should be considered for patients able to distinguish between the pictures or designs.

4. Ventilator patients draw strength from relationships with family or other persons.

Patients described times in which visitors helped them through the ventilator experience. Several patients described times when thinking about significant others helped them through times when they perceived lost power. One patient stated that knowing that his friends were praying for him strengthened his faith in God.

Relationships contributed to their sense of connecting with themselves as human beings instead of feeling dehumanized. Their feelings of being human enhanced their abilities to manage the stress and challenge of the situation. Intubated patients should be encouraged to think about and draw strength from their relationships. When possible, intensive care unit staff should consider extension of visiting hours to promote patient relationships and feelings of being human, thereby strengthening and empowering them to better manage the circumstances. The role of visitors in promoting patient well being should be considered when designing future intensive care units. Additionally, caregivers should continue to relate to patients as human beings instead of as part of the technology.

5. Knowledge of medical conditions and the ventilator experience contribute to patients' power during the ventilator experience.

Patients who were able to discuss their medical conditions or who had prior knowledge of the ventilator experience were better prepared to manage the associated stress. They were more confident in the outcome since the fear of the unknown was not as prominent. Patients were able to incorporate their knowledge into their thought processes and draw from it as they were on the ventilator. Eventually they were able to use their knowledge to help others. For example, one participant used his knowledge and

new experience to advise nurses and future ventilator patients. Other patients who had no knowledge of their conditions or of the ventilator experience did not share the same confidence in the outcome. More complete, timely, and continuous education should be given regarding patients' medical conditions and the ventilator, and should begin prior to hospitalization when possible. Patients awakening from anesthesia should be given clear and frequent instructions regarding presence of the endotracheal tube and ways of synchronizing breathing patterns. Staff interactions with patients should be geared toward educating patients and families thereby increasing the patients' perceptions of personal power during the experience.

6. Patients were comforted, strengthened, and felt less isolated by awareness of other ventilator patients.

Mechanically ventilated patients who experienced open concept intensive care units could oftentimes see and hear the staff or other ventilator patients, so they felt less alone in their situation. Knowing the staff were caring others promoted a sense of trust that staff would also care for them. Patients knew they could be seen and so were less concerned about being forgotten. One patient who was mechanically ventilated while in a closed concept unit developed an extreme lack of trust in staff after unsuccessfully attempting to alert them to the fact that she had aspirated. The patient's visitor left her in the room unattended to get help from the staff, which contributed to the anxiety of the situation. Consideration should be given to the importance of patients with similar treatment regimens when designing intensive care units or when assigning beds to patients. Open concept units were preferred by the patients within this study because

they knew caregivers would see them and there would be less risk of being forgotten.

Staff working in open or closed concept units should strive to be aware of and meet patient needs in a timely fashion to promote patient trust in caregivers.

Recommendations for Further Study

Further research is needed that addresses all aspects of the experience of mechanical ventilation. This preliminary study revealed specific areas in which research could be conducted.

1. Since this study focused on the ventilator experience as perceived by intensive care unit patients, further investigation of the ventilator experience within other settings such as the home is needed.
2. Examination of the ventilator experience should continue with open concept units, closed concept units, and specialty hospitals which house only ventilator patients to determine the effects of particular intensive care settings on patient experiences.
3. Most participants of the current study were Caucasian males. Research is needed with different populations to determine if differences exist in the experience.
4. The participants of the current study were over the age of 18 years. Additional exploration is needed with younger a population to determine if differences exist in the experience.
5. These participants were interviewed within 72 hours after the extubation. More qualitative inquiry should be done in which participants are interviewed after a

longer period since extubation to determine differences in perception of the experience.

6. These participants were mechanically ventilated for a few hours to a few days. Further research is needed to determine differences in the perception of the experience in patients mechanically for longer periods.
7. Qualitative examination focusing on methods of ventilator patient self-transcendence should be performed to determine and teach effective self-transcendence methods.
8. Multidisciplinary study on the spiritual assessment and needs of ventilator patients should be done to determine effective methods of holistic care. This researcher found no such instrument which assessed spirituality or spiritual needs within populations who were unable to communicate traditionally and in their own language.
9. Further study of teaching methods regarding the ventilator experience should be done to determine the best way of easing patients' fear of the unknown. Teaching interventions and methods should be developed based on that research.
10. Investigation regarding communication strategies with ventilator patients should continue to facilitate patient well-being by decreasing their feelings of frustration and self-focus.
11. Multidisciplinary research focusing on courage, trust, and hope in patients who experienced difficulty in weaning should be done to promote spiritual connection in the midst of greater adversity, anxiety, and physical stress.

12. Study of meaning of the experience of mechanical ventilation within the context of the patient's life should be done to develop interventions which promote patient reconciliation and peace with the event.
13. Continued investigation of the physical aspects related to the presence of the endotracheal tube should be done to determine interventions to effectively prepare patients for the discomfort associated with intubation, extubation, and life after.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL

Memorial Hermann
HEALTHCARE SYSTEM

December 15, 1998

Renae Schumann, R.N..
7600 Beechnut,
Chaplaincy Services
Houston, Texas 77074

Dear Ms. Schumann:

The Institutional Review Board of the Memorial Hermann Hospital System has received the requested revisions to the informed consent, and has unanimously approved the protocol, TWU-RS001: "Intensive Care Patients Perceptions of the Experience of Mechanical Ventilation." for which you are designated Principal Investigator.

Please be aware that it is your responsibility to keep the board informed of any changes related to research studies conducted at Memorial facilities. The IRB must report to the FDA any serious or continuing non-compliance by investigators. The Board will expect a study summary in December 1999.

Thank you for your cooperation. If you have any questions, please do not hesitate to contact either myself or the IRB Coordinator, at 713-932-3564.

Sincerely,



Naureen Ismail, R.N.
for James T. Heisler, M.D.
Chairman
Institutional Review Board
Memorial Hermann Hospital System

APPENDIX B
CONSENT FORM

TEXAS WOMAN'S UNIVERSITY

DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

Intensive Care Patients Perceptions of The Experience of Mechanical Ventilation Consent Form

I hereby authorize Renae Schumann, MSN, RN to interview me about my experience on a ventilator. I was informed that the interview will be audio taped. It is my understanding that I will be interviewed once for approximately one hour, and that a second interview may be required for clarification.

I understand that the interview will be conducted in the privacy of my hospital room. I understand that risks to me from participating in the study are fatigue, and emotional distress. I know that if I experience some anxiety or have questions during the interview, that adequate time will be allowed for me to ask these questions or to discuss concerns. I am free to interrupt the interview at any time, either to rest or to stop the interview. If I wish any rest period, the interview will be stopped until I wish to continue. I understand that the researcher, Renae Schumann will remain after the interview is completed to answer questions or to discuss any other concerns. Additionally, if I have any questions, I may call Renae Schumann at 713/776-5691 during business hours.

I was informed that confidentiality will be protected. Only a number will be placed on my data forms and audio tape. I know that this is necessary to keep my data separate. I further understand that my name will not appear on any data forms or identified by others. Therefore, care will be taken to keep all tapes locked in a file cabinet. I understand that no one besides the investigator and transcriber will have access to, or be able to listen to the tapes. I will not be identified anywhere in this research study. I understand that all audio tapes will be destroyed no later than two years after the conclusion of the study.

There is no direct benefit to me as a participant in this study. I will not be compensated, nor will I have to pay to participate. I understand that I am free to participate or not to participate. The choice is mine. If I choose to join the study, I may withdraw from the study at any time without penalty. My care will not be affected in any way if I do or do not participate.

Efforts will be made to prevent any complication that could result from the research. Medical services and compensation for injuries incurred as a result of participation in the research are not available. The investigator is prepared to advise me in case of adverse effects, which should be reported to her promptly. A telephone number where the investigator can be reached is listed in the beginning of this form.

An offer to answer all my questions regarding this study has been made. Should I have any questions or concerns regarding my rights as a study participant, I may contact a member of the Memorial Hermann Healthcare System Institutional Review Board at (713) 932-3564. If alternative procedures are more advantageous to me, they have been explained. A description of possible discomfort or risks reasonably expected has been discussed with me.

Participant's signature

Date _____

Principle Investigator

Date _____

Witness

Date _____

APPENDIX C
INSTRUMENTS

Intensive Care Patients' Perceptions of the
Experience of Mechanical Ventilation

DEMOGRAPHIC FORM

Age _____ Male _____ Female _____ Race: African American _____
Caucasian _____
Occupation _____ Hispanic _____
Asian _____
Other _____
Education Level: Less than High School _____
High School Graduate _____
Some College _____
College Graduate _____

Intensive Care Unit _____

Length of Time on Ventilator _____

Diagnosis/Reason for Ventilation _____

Other Medical Conditions _____

Previous Intubations _____

Number of Hours Extubated _____

Patient Description of Reason for Intubation _____

Medications _____

Contact Information for Follow Up _____

Intensive Care Patients' Perceptions of the
Experience of Mechanical Ventilation

PARTICIPANT INTERVIEW GUIDE

1. Please tell me about a typical day on the ventilator.
2. Please describe your thoughts while you were on the ventilator.
3. Please describe how you passed the time while you were on the ventilator.
4. How did you cope while on the ventilator?
5. What else can you tell me about the experience of mechanical ventilation?

PROMPTS

1. Can you tell me more about that?
2. What else can you tell me about the experience?