The Relationship of FIMS Scores and Quality of Life in Post Long-Term Ventilator Dependent Patients Who Were Discharged From a Rehabilitation Hospital

By

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Abstract

A retrospective study was conducted to determine the relationship between the Functional Independent Measure Systems (FIMS) and quality of life in post long-term ventilator dependent patients who were discharged from a rehabilitation hospital. The database from the hospital's medical records was used to obtain patient information on patients who were discharged home following long-term ventilator dependency.

Chronic ventilator dependent patients who were admitted to a rehabilitation hospital in northeast Ohio, and subsequently discharged home, were identified. A survey was conducted to determine the patient's quality of life following their discharge from the hospital. These patient responses were then correlated with a composite FIM score.

A total of eighteen post ventilator dependent patients responded to the survey that was conducted. Overall, the analysis revealed a statistically significant relationship existed between a higher composite FIM score and specific areas in post long-term ventilator dependent patient's quality of life.

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CHAPTER I

INTRODUCTION

Chronic ventilator dependency is a problem that affects many Americans. According to a Gallup Poll conducted for the American Association for Respiratory Care (AARC), there are nearly 12 million chronic ventilator dependent patients in the nations hospitals. This number of ventilator dependent patients accounts for a large percentage of today’s health care dollars. The current healthcare environment demands both proficient and efficient care providing the right care to patients who need care and for whom the care is likely to be effective. The risk of misallocation will occur if care is not indicated but is rendered or if care is not provided when a therapy is needed. Critical and efficient use of resources is demanded in today's society when resources are limited.

Many hospitals require that chronic ventilator-dependent patients be cared for in an intensive care unit (ICU), even though they may be medically stable. The ICU is expensive and often provides care that exceeds the requirements of these otherwise stable patients. Adult chronic ventilator-dependent patients have been hospitalized safely in alternative non-ICU sites for many years. These adult patient alternative hospital sites, usually involve a separate ventilator unit located in an acute care hospital, a freestanding regional weaning center, or a skilled nursing care facility.

Multiple conditions lead to prolonged mechanical ventilation. It is well known that severe acute lung injury, commonly referred to as "Adult Respiratory Distress Syndrome, results in respiratory failure requiring mechanical ventilation and is associated with high mortality (Newman, 1993). There have not been any studies that have identified the quality of life of the chronic ventilator dependent patient once they become weaned from ventilator support. Complications resulting in multi-system failure may also contribute to prolonging the course and worsening the prognosis for these patients with pulmonary dysfunction. (Bell, Coalson, Smith, and Johanson, 1983).

Statement of Research Problem

Chronic ventilator dependency has increased drastically in the United States over the last several decades. Advances in medicine have led to an increase in life expectancy. It is a major reason for prolonged life and an increase in the cost for hospitalization. In the midst of escalating healthcare costs, a need exists to address the impact of prolonged ventilator dependency on the patient's quality of life.

Statement of Purpose

The purpose of this study was to investigate the relationship of Functional Independent Measure Systems (FIMS) scores and quality of life in post long-term ventilator dependent patients discharged from a rehabilitation facility in northeast Ohio.

Hypothesis

Hypothesis to be tested: There is a positive correlation between FIM scores and quality of life in post long-term ventilator dependent patients who were weaned from mechanical ventilation and discharged home.

Delimitations of Study

Subjects of this study were as follows: (1) adult post-ventilator dependant patients discharged from the hospital home since 1994, (2) ages 48 years old to 84 years old, (3) both male and female, (4) residents in Trumbull, Mahoning or Columbiana counties, (5) all races, (6) patients who were presented to the hospital.

Limitations of Study

1. Only adult patients that presented to the study hospital are included. Those receiving medical care in other hospitals, extended care facilities, or long-term acute care hospitals are not included.
2. Subjects included only those patients who are diagnosed as ventilator dependent as the primary admitting diagnosis.
3. Only the years 1994 through December 2001 are included since there are no ventilator patients prior to this time at the primary site.
4. Self-reporting data might be subject to intentional or unintentional distortion.
5. Investigations rely on the patient population from one rehabilitation facility.
6. Results may possibly be biased due to healthier patients filling out the question are.
7. Sample size is limited.
8. Only one rehabilitation facility was included in the study.
9. Some of the former patients had died following discharge from the facility.
10. Subjects transferred to another facility are excluded due to the inability to accurately follow the subject's discharge status.

Assumptions of Study

Relative to this proposed study, the following assumptions were made:

1. The admitting physicians had properly and accurately diagnosed the subjects with chronic ventilator dependency.
2. The patients were accurately assessed for Functional Independent Measurement (FIM)scores upon admission.
3. The instrument used was appropriate for the populations studied.
4. Participants were accurate when filling out the questionnaire.
5. The sample size represented the population in northeast Ohio.

Operational Definitions

Apnea - absence of breathing due to airway obstruction

Airway edema - excess fluid in the lungs

Bronchospasm - muscular contraction of the airways leading to obstruction

Atelectasis - failure of expansion or resorption of gas from the lungs

Pulmonary infection - bacterial infection within the lungs

Pulmonary tumors - growth of tissue leading to airway obstruction

Myopathies - respiratory muscle dysfunction

Brain-stem lesion - causes depressed respiratory drive

FIMS - instrument tool for assessing the levels of independent performance of thirteen common motor self-care tasks and five common cognition tasks.

Mechanical ventilation - the use of a machine to induce alternating inflation and deflation of the lungs, to regulate the exchange rate of gases in the blood.

Ventilator dependence - the need for ventilator assistance for greater than 28 days (THE GALLUP ORGANIZATION, 1991).

Summary

Educating the ventilator dependent patient and his or her family may lead to a more efficient use of hospital services. As the family was made aware of the full spectrum of ventilator dependence and the importance of rehabilitation as it related to quality of life, they more readily made an informed decision when it came time to discharging a loved one from the hospital setting to a less critical environment.

Chapter II provides a review of the literature revealing the impact of ventilator dependence in America.

Chapter III presents the study design, sample, and tools used to measure a patients' perception of quality of life post ventilator dependence. The statistical methods used to evaluate the scores and their relationship to variables will be presented.

In Chapter IV, the results of the data analysis will be presented along with a discussion of post ventilator dependence and quality of life.

Chapter V discusses the summary of the study, the findings, limitations, and implications. Recommendations for future research are presented.

CHAPTER II

LITERATURE REVIEW

The purpose of this study was to investigate the relationship of the Functional Independent Measure Systems (FIMS) scores and quality of life in post long-term ventilator dependent patients discharged from a rehabilitation facility in northeast Ohio. Assessment of health related quality of life is a valuable tool to healthcare policy makers and epidemiologists when making decisions regarding strategic planning and initiatives to improve the costs, outcomes, and accessibility to healthcare delivery systems. This chapter contains a review of select literature related to respiratory diseases and health-related quality of life including those patients who were ventilator dependent. A brief historical overview of chronic ventilator dependence, the connection between the quality of life and illness, and the costs associated with long-term ventilator dependence in America's hospitals are included in this review.

Historical Overview

A ventilator was used to substitute for or optimize a patient's own breathing in order to maintain an adequate amount of oxygen in the blood. Demonstrations in animals as early as 1555 by Vesalius and 1667 by Hook showed that life could be sustained by inflation of the lungs with a bellows inserted into the mouth while the chest cavity is opened (Andreoli, Carpenter, Griggs, Loscalzo and Cecil, 2001). These first primitive attempts are the beginnings of ventilator therapy.

In humans, ventilator therapy was initially developed to allow physicians to operate on an open chest. Without proper inflation, the lungs would collapse upon opening the chest and the patient's condition would quickly deteriorate. Technological advances and greater attention to the importance of optimal ventilation led to improvements in respiratory therapy. The development of tank respirators in the 1920s and 30s was crucial in the treatment of polio patients who developed respiratory insufficiency (Hall and Wood, 1987).

The polio epidemics of the 1950's led to the development of ventilator technology and to new ideas about healthcare. People, who were once considered non-viable as patients, were now given hope of surviving. It was soon realized that respiratory polio survivors needlessly occupied expensive hospital beds when they could have been cared for at home with attendants, equipment maintenance, and other support services for one-third of the hospital cost (Henneman, Dracup, Ganz, Molayeme and Cooper, 2002).

Thus, respiratory polio survivors were sent home with a variety of breathing aids (iron lung, chest cuirass, or rocking bed). They pursued their education and careers, married and raised families, traveled and contributed to their communities. As the years went by, these former patients, now long-term ventilator users, helped refine ventilator equipment in size, portability, operation, and cost (American Association of Respiratory Care, 1991).

Sometimes patients still could not breathe on their own after the acute illness was over despite efforts to restore spontaneous breathing. Mechanical ventilation assisted these patients until which time their spontaneous breathing effort returned. A subset of patients were no longer required to reside in ICU, since they were stable, but still needed mechanical ventilation to assist their breathing for a brief period or time. A final subset of patients had stable, longer-term (chronic) conditions that made them unable to breathe on their own for a prolonged period of time.

Over time, with the professional support of physicians and respiratory therapists, some chronic ventilator-assisted individuals were able to become less dependent on the ventilator and breathed on their own for substantial portions of every day. Other patients were required only nocturnal ventilator support. While another subgroup was never liberated from mechanical ventilation but were still cared for in a setting outside of acute care.

These developments, coupled with increased recognition of the cost benefits of home care, enabled individuals with high spinal cord injuries, Amyotrophic Lateral Sclerosis (ALS), Chronic Obstructive Pulmonary Disease (COPD), muscular dystrophy, cystic fibrosis, infants and children with Bronchopulmonary dysplagia (BPD), and acid-maltase deficiency, to live at home in their communities.

Advances in positive pressure ventilation and noninvasive forms of ventilation, such as face and nasal masks, have increased the independence and quality of life. At the same time it decreased the need for unnecessary tracheostomies (Andreoli, Carpenter, Griggs, Loscalzo and Cecil, 2001).

Mechanical ventilation was still required when a patient's spontaneous efforts were unable to sustain adequate ventilation of the lungs. Patients had medical conditions that required 24-hour mechanical ventilation for many months or years, or even for a lifetime. Conditions such as stroke and spinal cord injuries damaged the nerves that controlled breathing and made spontaneous breathing impossible for an extended period or for life. Chronic stable illnesses, such as neuromuscular disorders and chest wall deformities, and/or advanced age, made long-term mechanical ventilation necessary for extended periods or permanently. Chronic illness often required recurrent ICU hospitalizations, frequent repeated treatments with mechanical ventilation and repeated attempts to wean from the ventilator.

In a December 1990 poll, researchers found that there were more than 11,400 chronic ventilator dependent patients in the nation's hospitals (The Gallup Organization, 1991). Following determination that these patients were medically stable, and no longer in need of the critical care that they had been receiving, discharging them to an appropriate facility remained difficult. With few skilled nursing facilities offering beds for chronic ventilator dependent patients, because of limited reimbursement for their care, the patient waited approximately 35 days before a bed is available (The Gallup Organization).

Patient Ventilator Support Treatment Objectives

The following subsections will discuss the treatment objectives, prognosis, mechanical ventilation process and indications for treatment, quality of life measures, and functional independence measure.

The objective of ventilator therapy is to permit lung and airway healing. However, the specific objective of ventilator therapy was dependent upon the specific condition one was trying to treat. As such, there can be several different treatment objectives (Yang and Tobin, 1991).

One possibility was to reverse hypoxemia, a condition of low blood oxygen levels arising from airway obstruction. Control of the airway was regained using ventilator therapy. A mechanical ventilator helped by decreasing the energy required to breathe. It assisted the patient having respiratory muscle fatigue and difficulty breathing (Jurbin, 1997).

Also ventilator therapy was also used to prevent and reverse some forms of atelectasis. The ventilator helped to increase the flow of oxygen and increase expansion of affected lung areas. Additionally, this procedure aided oxygen flow to the blood.

Prognosis

The prognosis for a patient on ventilator therapy was different for each patient. For those patients who remained on long-term ventilatory support (more than three weeks), the endotracheal tube was usually replaced by a tracheostomy (Gluck and Corigan, 1996). This tracheostomy allowed the patient the ability to speak and swallow. The process of returning a patient to normal breathing following ventilation (weaning) was then initiated once the patient had recovered from respiratory difficulties. Weaning was the word used to describe the process of gradually removing the patient from the ventilator and restoring spontaneous breathing after a period of mechanical ventilation. One method for weaning involved allowing the patient to breathe oxygen on his or her own and monitoring their respiratory function to make sure it was back to normal before extubation. Another method was to gradually decrease the rate of ventilatory support over a period of days, while supplying full support at night.

Physicians and the ICU respiratory care specialists helped patients to wean when weaning was determined to be medically appropriate (Salipante, 1995). While patients with some conditions were weaned from mechanical ventilation after a few days to a week in the ICU, patients with other conditions could not be taken off the ventilator quickly. (Gracey, Hardy, Naessens, Silverstein and Hubmayr, 1997). Patients with stable chronic medical conditions were more likely to become dependent upon life support equipment when they had an additional exacerbation of their disease.

Quality of Life and Illness

For elderly patients, ventilator-related losses came at a time when other serious losses-retirement, income, social status, friends, or spouse-were accumulating (Wilson,1995). The ventilator patient's greatest psychological problem was the lack of control and the inability to do anything for oneself or for anyone else.

However, for those who suffered severe impairment or even complete failure of respiratory function, the ventilator (or respirator) was literally the link between life and death. Mechanical ventilation was able to effectively assist or replace normal spontaneous breathing by taking over the vital role of the respiratory muscles, inducing rhythmic inflation and emptying of the lungs. It also provided the natural processes of humidification, filtration, and the warming of inspired gas if intubation (use of an inserted tube) and ventilation were employed (Shapiro, Harrison and Trout, 1999).

For the families of the ventilator dependent, the anxiety level ran high. Family needs and situational anxiety were significantly related when there was a loved one in an intensive care unit and ventilator dependent (Beatty, Schechter and Whitaker, 1996). Furthermore, worries, trait anxiety, age and family needs explained 38% of the variation of situational anxiety. As well, spiritual needs and situational anxiety explained 33% of the variation of family needs (Moody, Lowry, Yarandi and Voss, 1997).

Family members identified many similar important needs, such as (1) the need to have questions answered honestly, (2) the need to be called at home about changes in the patient's condition, and (3) the need to know why things were done for the patient (Iregui, Malen, Tuteur, Lynch, Holtzman and Kollef, 2002).

Family members also indicated that some needs were both more important but less satisfactorily met. The need to know the occupational identity of staff members, directions as to what to do at the patient's bedside, and having friends for support also ranked high in elevating family stress.

Mechanical Ventilation Process

Mechanical ventilation (respirator) delivered inspiratory gases directly into the patient's airway. The patient was connected to the ventilator by an endotracheal tube passed through the nose or mouth into the trachea. If prolonged ventilation was likely to be required, a tube was inserted into an opening made in the trachea; an operation called a tracheostomy. Conscious patients, and those patients nearing the end of anesthesia, were usually given muscle-relaxant and sedative drugs to prevent them from resisting the insertion and irritant presence of the endotracheal tube. This technology was used to sustain persons whose spontaneous breathing was inadequate or had stopped altogether due to acute or chronic diseases of the neuromuscular, neurologic, or pulmonary system, or due to anesthesia, trauma or high-risk surgical procedures. (Estaben, Reyes and Roca, 1999). For the ventilator patients who did not need to be confined to bed, portable ventilators allowed mobility and a variety of physical activities.

Four phases of the respiratory cycle that were controlled:

1) The inspiratory phase
2) The changeover from inspiration to expiration
3) The expiratory phase
4) The changeover from expiration to inspiration.

(Andreoli, Carpenter, Griggs, Loscalzo and Cecil, 2001).

For the patient during the inspiratory phase a positive gas pressure caused oxygen to flow into the patient's lungs; the length of inspiration was determined by a set time interval, a pressure limit, or a volume limit. (Seneff, Zimmerman, Knaus, Wagner and Draper,1996).

Each of these methods worked to insure that the patient received an optimal amount of oxygen with each breath. There was also a safety feature often termed a "pop-off" valve which protected the patient from any excessive pressure build up should a mechanical malfunction occur.

The expiratory phase was usually a passive process, meaning that the elasticity of the chest and lungs forced the air out of the lungs unassisted. However, expiration can be assisted, if needed, by adding a negative pressure to the ventilator circuit, or by adding a slight positive pressure so that the airway did not collapse during exhalation (Estaben, Reyes and Roca, 1999). The negative pressure improved gas exchange within the patient's lungs.

Ventilators function in several different capacities depending on the patient's need for assisted breathing. Some ventilators cycled automatically, regardless of the patient's need or desire for a breath; these were termed "control" ventilators and they guaranteed a minimum level of ventilation for the patient.

"Assist" ventilators were designed to initiate the patient's own voluntary inspiration and simply aided them in effective breathing. "Assist-Control" ventilators combined the functions of the two previous types and can assist a patient’s spontaneous breathing or breathe for them completely if they stop.

Finally "intermittent mandatory" ventilation was a combination of spontaneous and controlled breathing which allowed the patient to breathe unassisted, but periodically gave a mandated breath. For many years, intermittent mandatory ventilation was the mainstay in liberating people from mechanical ventilator support.

Indications for Treatment

Mechanical ventilation was used to insure an arterial oxygen saturation of greater than 88%. There were many reasons why an individual’s blood oxygen level became depressed. Mechanical ventilation therapy was often necessary in the following cases: apnea, airway edema, bronchospasm, atelectasis, pulmonary infection, pulmonary tumors, myopathies, drug overdose, and brain-stem lesion. Arterial oxygen saturation levels that fell below 88% were considered detrimental (Henneman, 2001).

A person's experience of severe respiratory impairment and treatment with mechanical ventilation, as with other life-threatening illness and treatment, depended on a variety of personal and environmental factors. Among the most important were the person's personality, prognosis, level of consciousness, social support, the quality and sensitivity of the care received, and treatment setting. (Scheinhorn, Chao, Hassebor and Gracey, 2001). Some individuals coped better or worse with the physical, psychological, and social stresses to which they were subjected.

In the care of many acutely ill patients, mechanical ventilation lasting only for a few hours or a few days was sufficient and the ventilator could be removed and normal breathing resumed. Unfortunately, for those patients whose underlying disease was chronic, they became sometimes unexpectedly, chronically ventilator dependent. Their continuing need for mechanical ventilation was 24 hours a day or was limited to use during sleep or intermittently through the day.

Ventilator Costs

The estimated monthly cost of long-term care facility placement of ventilator dependent patients, (in 1995 dollars), ranged from $13,578 to $27,133 (Henneman, Dracup, Ganz, Molayeme and Cooper, 2002). In the United States, Medicaid reimbursement in 1990 was estimated to cover only 46% of the costs of care of the approximately 11,000 chronic ventilator-dependent patients in acute care hospitals (Hill, 1996).

Patients discharged from acute care facilities to home were often delayed by a lack of community resources, and to long-term care facilities by a shortage of beds. In 1990, this delay was estimated to average $27,000 per patient to the cost of acute care (Hill). This delay caused healthcare costs to total more than nine million dollars (The Gallup Organization). Researchers found a 3.6-day shorter length of stay for ventilator dependent patients saved Medicare $97.9 million dollars in one year.

Research found that once a chronic ventilator-dependent patient was medically able to be discharged, it took an average of 35 additional days to place that patient in an alternative care site such as a skilled nursing facility. That 35-day delay translated into unnecessary hospital costs. One of the primary reasons for those placement delays, and hence the additional Medicare expenses, was inadequate reimbursement policies can leading to the practice of facilities choosing to accept only the most stable, lower-cost patients or patients whose conditions receive appropriate Medicare reimbursements.

Quality of Life Measures

Although the importance of quality of life was broadly acknowledged, skepticism and confusion remained about how quality of life was measured and its usefulness in medical research (Kanarek, Sockwell and Jia, Centers for Disease Control and Prevention, 2000). Varying responses on how the quality of life was measured reflected important conceptual and methodological limitations of a person's current concept of quality of life. A simple framework that described the core elements of quality of life related to the patient's health status was used to evaluate quality of life measurement as it was currently conducted. (Cohen, Bari, Strosberg, Weinberg, Wacksman, Millstein and Fein, 1991).

Mechanical ventilation was a mixed blessing as it's potential good was not always good enough. While offering hope of prolonged life, mechanical ventilation had drastic implications for the quality of life. Whether a particular individual benefited from mechanical ventilation was initially a medical judgment. Often, however, no clear diagnosis had been established, and even when one had, the individual's prognosis remain highly uncertain. If the patient, family members, physicians, nurses, and other professional caregivers had not agreed with each other on the prognosis, the decision making reverted from the medical expertise to the realms of psychology, ethics, religion, economics, and law (Moody, McCormick and Williams, 1990).

While there was neither a precise nor agreed upon definition of quality of life, there were essentially two kinds of information, the functional status of the individual and the patients' appraisal of health as it affected his or her quality of life. In addition, current questionnaires were used in quality of life assessments generally embody one or both of the following operational definitions-quality of life as an individual's behavior or level of functioning or quality of life as an individual's perceived health status or well-being. Measuring someone's ability to perform common tasks or activities was the objective, while asking patients to rate the affects of health status on personal well-being was more subjective. Most early measures of health status, as well as some contemporary quality of life instruments, were designed to measure objectively the adequacy of individuals' functioning across physical, occupational, and interpersonal domains. Understanding the effects of health status on quality of life was imperative. Assessing physical functioning involved measuring the ability to perform specific tasks as well as less easily defined concepts that were related to an individual's role. In many respects, measurement of physical functioning was similar to assessment of physical disability. (Anderson, Fouts, Romeis and Brownson, 1999).

The alternative, or complementary, perspective on quality of life assigned central importance to an individual's subjective appraisal of their state of health. The subjective nature of quality of life was perhaps best understood as focusing on how ill or disabled patients say they felt in the context of their personal lives, as distinct from external attempts to quantify stage or degree of illness or disability. (Beatty, Schechter and Whitaker, 1996). A patient's appraisal of his or her mental well-being was usually interpreted as the absence of psychological distress (that is, anxiety, depression, anger) and also included emotional ties and social support.

How patients evaluate their quality of life also changed over time. The internal standard by which patients appraised their current state shifted and the same questionnaire items on well-being elicited different answers over time (Ware, 1994). The more severe a patient's illness became, the more different the responses became on the same appraisal system. Self reported information obtained from quality of life questionnaires was and will continue to be essential.

Health related quality of life instruments were designed to assess the overall quality of life, including facets such as emotional functioning, social role functioning, and activities of daily living, or only domains directly related to a particular disease (Anderson, 1995). For instance, specific chronic respiratory instruments assessed aspects such as dyspnea, cough, sputum production, exercise tolerance, and mood. Disease-specific questionnaires were likely to be more sensitive to particular symptoms and to small responses to therapeutic interventions; the generic instruments had the advantage of being thoroughly tested in several clinical settings and populations (Ware, 1994).

Functional Independence Measure (FIM)

The Functional Independence Measure (FIM) instrument (Appendix B) was a tool for assessing the levels of independent performance of thirteen common motor self-care tasks and five common cognition tasks. It required training for an observer to assign reliable and accurate levels of functioning for a person with a disability. The instrument was used to judge the degree of need for assistance from another person, and it served as a basis for judging whether the person's level of independence had improved or not after a rehabilitation intervention.

The FIM instrument was an 18-item, seven level ordinal scale. It was the product of an effort to resolve the long-standing problem of lack of uniform measurement and data on disability and rehabilitation outcomes. The FIM instrument emerged from a thorough developmental process overseen by a National Task Force of rehabilitation research. The National Task force reviewed 36 published and unpublished functional assessment scales before agreeing on an instrument.

The FIM instrument was intended to be sensitive to change in an individual over the course of a comprehensive inpatient medical rehabilitation program. The FIM instrument was designed to assess areas of dysfunction in activities that commonly occur in individuals with any progressive, reversible or fixed neurologic, musculoskeletal and other disorders. One limitation relative to using the FIM instrument in evaluating a patient is that it was not diagnosis specific.

By design, the FIM instrument includes only a minimum number of items. It was not intended to incorporate all the activities that could possibly be measured, or that might need to be measured, for clinical purposes. Rather, the FIM instrument was a basic indicator of severity of disability that was administered comparatively quickly and therefore was used to generate data on large groups of people.

Severity of disability changes during rehabilitation. The data generated by the FIM instrument was used to track such changes and analyze the outcomes of the patient's rehabilitation. If help was needed, the scale quantifies that need. The need for assistance (burden of care) translates to the time/energy that another person expended to serve the dependent needs of the disabled individual to achieve and maintain a certain quality of life.

The FIM instrument was measure of disability, not impairment. This instrument was intended to measure what the person with the disability actually did, whatever his or her diagnosis or impairment, not what he or she ought to be able to do, or might have been able to do if certain circumstances were different. Experienced clinicians were aware that a depressed person could do many things he or she was not doing, but nevertheless the person was assessed on the basis of what he or she actually did.

All FIM instrument items were completed. It was designed to be discipline-free, measurable and usable by any trained clinician, regardless of discipline. While the

FIM instrument remained disciple-free, specialized clinicians better assessed certain areas. A speech pathologist assessed the communication items, whereas a nurse was more knowledgeable with respect to bowel and bladder management, a physical therapist had the expertise to evaluate transfers, and a occupational therapist scored self-care and social cognition items, the assessment was divided among them.

Composite FIM scores (CFIM)

FIM scores were developed to measure disability along various dimensions - Self-Care: eating, grooming, bathing, dressing-upper, dressing-lower, and toileting, Sphincter Control: bladder and bowel, Transfers: bed, chair and wheelchair, toilet, tub/shower transfers, Locomotion: walking/wheelchair, and stairs, Communication: comprehension and expression, Social Cognition: social interaction, problem solving and memory. From these eighteen items thirteen defined disability in motor functions and five defined disability in cognitive functions.

There was not a single value that evaluated a patient's impairment. With this in mind, the researcher looked at the 18-item seven level ordinal scale for each individual patient. FIM scores for each dimension were then averaged to construct a composite FIM score (CFIM) for each patient.

This subsequent number was used in establishing a distinct value that was entered into SPSS as a CFIM score.

Qualitative and Quantitative Questionnaires

Opposing Views

There has been considerable debate over whether qualitative and quantitative methods can and should be assessed according to the same quality criteria. Extreme relativists hold that all research perspectives were unique and each was equally valid in its own terms, but this position meant that researchers cannot derive any unequivocal insights relevant to action, and it would therefore command little support among applied health researchers. (Schechter, Beatty and Willis, 1998). Other than this total rejection of any quality criteria, it was possible to identify two broad, competing positions, for and against using the same criteria. Within each position there was a range of views.

Advocates of the antirealist position argued that qualitative research represents a distinctive paradigm and as such were not and should not be judged by conventional measures of validity and reliability (Schechter, Beatty and

Willis, 1998). At its core, this position rejected realism--a belief that there was a single, unequivocal social reality or truth that was entirely independent of the researcher and of the research process; instead there was multiple perspectives of the world that were created and constructed in the research process (Ware, 1994). Those relativists who maintained that assessment criteria were feasible but that distinctive ones were required to evaluate qualitative research had put forward a range of different assessment schemes. In part, the choice and relative importance of different quality criteria of quality depended on the topic and the purpose of the research. Attempts have been made to organize these quality criteria that were open to challenge (for example, it is arguable whether all research should be concerned with developing theory). At the same time, many of the criteria listed are not exclusive to qualitative research.

Other authors agreed that all research involved subjective perception and those different methods produced different perspectives, but, unlike the antirealists, they argued that there was an underlying reality, which was studied. The philosophy of qualitative and quantitative researchers should be one of "subtle realism"--an attempt to represent reality rather than to attain "the truth"

(Ware, 1994). From this position it was possible to assess the different perspectives offered by different research processes against each other and against criteria of quality common to both qualitative and quantitative research, particularly those of validity and relevance (Ware, 1994). However, the means of assessment may be modified to take account of the distinctive goals of qualitative research. Whether quality criteria should be applied to qualitative research, which criteria was appropriate, and how they should be assessed was frequently debated. It was unwise to consider any single set of guidelines as definitive.

Summary

The health community has not properly addressed the quality of life in post long-term ventilator dependent patient. There is much written concerning quality of life in certain patient populations, but there remains a lack of research on the long-term ventilator patient. Determining the quality of life in post long-term ventilator dependent patients in relationship to FIM scores was an area that required research.

Information from this study will be used to investigate the relationship of the FIM instrument and quality of life in post long-term ventilator dependent patients.

Chapter III provides the study design, sample, and tools used. The statistical methods used to determine the relationship between FIM scores and quality of life are also presented.

Chapter IV reveals the results of the data analysis along with a discussion of the relationship of FIM scores and the health and quality of life of post ventilator dependent patients.

Chapter V discussed the summary of the study, the findings, limitations, and implications. Recommendations for future research are presented.

CHAPTER III

METHODOLOGY

The purpose of this study was to investigate the relationship of Functional Independent Measure Systems (FIMS) scores and quality of life in post long-term ventilator dependent patients discharged from a rehabilitation facility in northeast Ohio. This chapter provides a description of the methodology used in the study to determine the quality of life in post long-term ventilator dependent patients in relationship to FIM scores. In addition, this chapter gives an explanation of the study design, population, instrument, reliability and the statistical methods used to measure the relationship between post ventilator dependence and quality of life in relation to admission FIMS scores. Lastly, this chapter describes the various measures and procedures used to analyze the relationship between CFIM scores and quality of life.

Research Design

A retrospective study was done to examine the data of post long-term ventilator dependent patients who were admitted and subsequently discharged from a rehabilitation hospital. A database for ventilator dependent patients was used to collect dates in order to determine the effects on the quality of life on patients who were discharged home without the need for ventilator assistance. The researcher chose the MOS SF-36 Health Survey for administration to subjects. The form contained 36 health and quality of life questions and was mailed in May 2002. Subjects were given two weeks to respond at which time a second postcard was distributed.

Subjects

The age of the patients range from early adulthood (18 years old) through and including geriatrics (>60 years old), who presented to the hospital as ventilator dependent. Both males and females are included. The sampling was inclusive of all payer types (private insurance, Medicare/Medicaid, and self pay).

Instrument

The instrument used was the MOS SF-36 Health Survey (APPENDIX C) which was developed in 1993 by John E. Ware, Jr., Ph.D., to evaluate the benefits of specific treatments and of the healthcare delivery system in terms of the extent to which changes in a patient's functioning or well-being met his of her needs and expectations. Two principal objectives of the MOS SF-36 survey were (1) to determine whether variations in a patients' outcomes were explained by differences in the system of health care delivery, provider training, and variations in styles of practice; and (2) to develop more practical tools for the routine monitoring of patient outcomes (Ware, 1994).

The MOS SF-36 Health Survey covered the following areas: limitations to physical activities because of health problems; role limitations due to physical health problems; bodily pain; general health perceptions; vitality (energy/fatigue); limitations in social activities because of physical/emotional problems; role limitations due to emotional problems; and mental health (psychological distress and psychological well-being).

MOS SF-36 Health Survey Reliability

Considerable evidence supported the validity of the MOS SF-36 Health Survey with a level of agreement for item inclusion among experts to be equal to or exceeds .80 (Ware, 1994). Test-retest reliability was estimated using the internal consistency method and Cronbach’s coefficient alpha. The median of the reliability coefficients across most studies for the MOS SF-36 equals or exceeds .80 with the exception of the social functioning scale, which is a two-item scale, was .76.

Reliability and Validity of FIM

Reliability has been shown to be high in the FIM instrument, especially in the use of Rasch analysis (Heinemann, Linacre, Wright, Hamilton, and Granger, 1993). High internal consistency with a Cronbach's value of a =0.93 for overall admissions and a =0.95 for discharges (Dodds, Martin, Stolov and Deyo, 1993). Inter-rater reliability has been shown to range from .89 to 1.0. A meta-analysis of eleven studies showed a median inter-rater reliability for the total FIM score of 0.95, a median test-retest reliability of 0.95, and an equivalence reliability of 0.92 (Ottenbacher, Hsu, Granger and Fiedler, 1996).

Researchers have shown that the FIM instrument was able to discriminate patients on the basis of age, comorbidity, and discharge destination. Through Rasch analysis, FIM scores decreased with ascending injury level (Dodds, Martin, Stolov and Deyo). Also, differences were seen in difficulty of specific items for certain impairment groups (Heinemann, Linacre, Wright, Hamilton, and Granger). Construct validity was demonstrated through strong correlations between burden of care and a measure of disability (r values ranging from 0.40 to 0.60). (Heinemann, Kirk, Hastie, Semik, Hamilton, Linacre, Wright, and Granger, 1997).

Survey Administration Procedure

Subjects chosen for this study were those patients who had presented to the hospital with a primary diagnosis of ventilator dependence. Ventilator dependent patients who, during the study time, had a primary diagnosis other than ventilator dependence or who are transferred and subsequently readmitted as ventilator dependent, were excluded from the research due to the possibility of additional effects on the subjects quality of life post discharge. Since the study was retrospective in nature, current ventilator dependent patients, who were weaned from mechanical support but remained within the hospital setting, were not contacted for inclusion in this study.

Upon approval of the participating hospital's Research Committee and University's Research Committee (Appendix A), the thesis committee approved the distribution of the survey. The surveys were distributed via mail along with a self-addressed stamped envelope. Included in the survey was an informed consent form that stated that their participation was totally voluntary, and their participation or non-participation in the survey did not affect any past or future medical treatment. If the patient chose not to participate, they simply did not return the study. The participants were also permitted to withdraw consent and discontinue participation at any time. The consent form briefly explained that the survey was designed to ascertain the overall health of the patient since their discharge from the hospital.

Summary

In this chapter, the research methods used to determine health and quality of life of post ventilator dependent patients were identified as well as FIM scores. Information obtained from this study provided baseline data explaining the relationship between a CFIM score and quality of life in post long-term ventilator dependent patients.

In Chapter IV, the results of the data analysis will be presented along with a discussion of post ventilator dependence and quality of life.

Further summarization and conclusion of the study findings are presented in Chapter V. The final chapter also includes implications of the study along with recommendations for further research.

CHAPTER IV

ANALYSIS OF DATA

The purpose of this study was to investigate the relationship of the FIM instrument scores and quality of life in post long-term ventilator dependent patients discharged from a rehabilitation hospital in northeast Ohio. Information from the completed MOS SF-36 Health Survey was used to determine the health and quality of life in post long-term ventilator dependent patients who were discharged from an inpatient rehabilitation facility. The Statistical package for the Social Sciences (SPSS, 2000) was used to analyze the data. The analysis consisted of Pearson's Product Moment Correlation and Partial Correlations.

Demographic Profile of the Sample Population

A total of 201 patients were admitted to the ventilator program from September 1994 through December 2001. Of these, 72 patients qualified to participate in this study according to the criteria above, and a survey was mailed to each. Eighteen surveys were returned for a return rate of 25%.

The demographic data revealed the patients ages ranged from 48 years to 84 years with a mean age of 69.7 years.

Eleven males (61%) and seven females (39%) completed and returned the survey. Sixteen Caucasians (89%)and two African-Americans (11%)completed and returned the survey. Additionally, the range from the time of discharge to the filling out of the MOS SF-36 survey was from 12 months to 74 months with a mean of 42 months. These statistics are summarized in Table 1.

Table 1. Demographic Data of Post Ventilator Dependent Patients

Variable	n	Percent
Age		
48 - 59	2	11.11%
60-69	7	38.89%
70-79	7	38.89%
80 and >	2	11.11%
Gender		
Male	11	61.11%
Female	7	38.89%
Ethnicity		
Caucasian	16	88.89%
African-American	2	11.11%
Post Discharge		
12-24	7	38.89%
25-48	4	22.22%
49-74	7	38.89%

Descriptive Statistics

The response rate was low at 25%(n=18), so the results, while suggestive, must be interpreted with caution. A

Pearson's Product Moment Correlation was used to evaluate the relationship between CFIM scores and the health and quality of life in post long-term ventilator dependent patients using the MOS SF-36 health survey. The results indicated that there was a positive correlation between a CFIM score and several components of the MOS SF-36 health survey. A positive Pearson's Product Moment Correlation resulted in a significant relationship between CFIM scores and three variables of the MOS SF-36 health survey at the .01 level: physical functioning (r= .597), social functioning (r=. 576) and role emotional (r=. 763). Two additional variables were statistically significant at the .05 level. Role-physical (r=. 576) and bodily pain (r=. 515). The data now supported the research hypothesis (Table 2).

Table 2. Relationship of CFIM and MOS SF-36 survey

Variables	Composite FIM R
Number of Months Since Discharge	-0.156
Sex	0.066
Age	-0.062
Physical Functioning	.597**
Role - Physical	.576*
Bodily Pain	.515*
General Health	0.448
Vitality	0.442
Social Functioning	.696**
Role Emotional	.763**
Mental Health	0.265

* $p<0.05$ ** $p<0.01$

Summary

A total of eighteen post long-term ventilator dependent patients were studied. Demographic data reflected that the subject's ages ranged from 48 years to 84 years with a mean age of 61.1 years. The population consisted of 61.1% males to 38.9% females. Caucasians accounted for 89% of the sampling while African-Americans accounted for 11% of the sampling. The range from the time of discharge to the filling out of the MOS SF-36 survey was from 12 months to 74 months with a mean of 42 months. In data analysis, it was revealed that overall, there was a significant correlation between a composite admission FIM score, and the physical functioning, social functioning and role emotional in post long-term ventilator dependent patients.

The study is further summarized in Chapter V. Conclusions of the study are presented as well as recommendations for further study.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENTATIONS

Summary

Chronic ventilator dependency has increased significantly in the United States over the last several decades. Advances in medicine have led to an increase in life expectancy. It is a major reason for prolonged life and an increase in the cost for hospitalization. In the midst of escalating healthcare costs, a need exists to address the impact of prolonged ventilator dependency on the patient's quality of life.

The purpose of this study was to investigate the relationship of the FIM instrument and quality of life in post long-term ventilator dependent patients who were discharged from a rehabilitation hospital. Selected sociodemographic variables (age, gender, and ethnicity) along with selected healthcare measures (physical functioning, role - physical, bodily pain, general health, vitality, role-emotional, and mental health) were looked at.

The hypothetical approach to the study was that there existed a relationship between higher CFIM scores and quality of life in post long-term ventilator dependent patients. Information obtained from the database provided data to determine the effects of higher CFIM scores and quality of life as measured by the MOS SF-36 Health Survey.

Conclusions

Information obtained from the study revealed the following:

- There was a positive correlation between CFIM and post long-term ventilator dependent patient's various physical activities.
- A strong positive correlation existed between a CFIM and a patients social functioning.
- A statistically significant correlation existed between a CFIM and post long-term ventilator dependent patients' role-emotional in which problems, or lack of problems, with work or other daily activities resulted in emotional problems.

Implications

Overall, the findings of this research demonstrated favorable results: There was a statistically significant correlation between CFIM scores and post long-term ventilator dependent patients quality of life. This study found seven common roles and activities that demonstrated highly suggestive correlations: (1) physical functioning, (2) role-physical, (3) bodily pain, (4) general health, (5) vitality, (6) role-emotional, and (7) mental health. This study found some activities were more apparent than others in a post ventilator dependent patient's quality of life following their discharge. The reader must keep in mind that even though the data is suggestive that a positive correlations exists, there was limited sampling in this study. Not only was the response rate low and the sample small, but the sample was probably biased toward healthier patients since less able and functioning patients would be less inclined to complete and return the survey; indeed these worst of the post ventilator patients probably died before receiving the survey.

Recommendations for Further Research

More and expanded studies to determine the relationship between CFIM and quality of life are warranted. It is not clear whether the scope of this study accurately reflects the post long-term ventilator patient in northeast Ohio. A more comprehensive study of each of the eighteen FIM system elements and their correlation to the MOS SF-36 Health Care Survey as well as follow-up closer to the patient's discharge date are needed.

Future investigations could improve on the limitations of this study. Evaluation of this patient population closer to their hospital discharge date would assist in including those patients who had died prior to the distribution of this survey. In additions, a comparison of admission and discharge CFIM and the MOS SF-36 Quality of Life Survey would provide additional information as to the former patients progression or regression post discharge.

With limited healthcare resources available and the potential for an increase in life expectancy, early identification of a patient's quality of life post hospitalization is needed. As a practical implication, these findings imply the need for CFIM prior to patient's admittance to a rehabilitation hospital for ventilator weaning.

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APPENDIX A

HUMAN SUBJECTS

YSU

Youngstown State University / One University Plaza / Youngstown, Ohio 44555-0001
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October 28, 2002

Dr. Carol Mikanowicz, Professor, Principal Investigator
Mr. Thomas E. Knoske, Student, Co-Investigator
Department of Health Professions
UNIVERSITY

RE: HSRC Protocol #29-2002

Dear Dr. Mikanowicz and Mr. Knoske:

The Human Subjects Research Committee of Youngstown State University has reviewed your response to their concerns regarding the above mentioned protocol titled "The Health and Quality of Life in Post Long-term Ventilator Dependant Patients Who Were Discharged From a Rehabilitation Setting." The Committee has reviewed the modifications you provided and determined that your protocol now fully meets YSU Human Subjects Research guidelines. Therefore, I am pleased to inform you that your project has been fully approved.

Any changes in your research activity should be promptly reported to the Human Subjects Research Committee and may not be initiated without HSRC approval except where necessary to eliminate hazard to human subjects. Any unanticipated problems involving risks to subjects should also be promptly reported to the Human Subjects Research Committee.

We wish you well in your study.

Sincerely,

Peter J. Kasvinsky
Dean, School of Graduate Studies
Research Compliance Officer

PJK:cc

C: Mr. Joseph Mistovich, Chair
Department of Health Professions

APPENDIX B

FUNCTIONAL INDEPENDENCE MEASURE

	ADMISSION	DISCHARGE	GOAL
SELF-CARE			
A. Eating	☐	☐	☐
B. Grooming	☐	☐	☐
C. Bathing	☐	☐	☐
D. Dressing - Upper	☐	☐	☐
E. Dressing - Lower	☐	☐	☐
F. Toileting	☐	☐	☐
SPHINCTER CONTROL			
G. Bladder	☐	☐	☐
H. Bowel	☐	☐	☐
TRANSFERS			
I. Bed, Chair, Wheelchair	☐	☐	☐
J. Toilet	☐	☐	☐
K. Tub, Shower	☐	☐	☐
LOCOMOTION			
L. Walk/Wheelchair	☐	☐	☐
M. Stairs	☐	☐	☐
COMMUNICATION			
N. Comprehension	☐	☐	☐
O. Expression	☐	☐	☐
SOCIAL COGNITION			
P. Social Interaction	☐	☐	☐
Q. Problem Solving	☐	☐	☐
R. Memory	☐	☐	☐

FIM LEVELS

No Helper

- 7 Complete Independence (Timely, Safely)
- 6 Modified Independence (Device)

Helper - Modified Dependence

- 5 Supervision (Subject = 100%)
- 4 Minimal Assistance (Subject = 75% or more)
- 3 Moderate Assistance (Subject = 50% or more)

Helper - Complete Dependence

- 2 Maximal Assistance (Subject = 25% of more)
- 1 Total Assistance (Subject less than 25%)

APPENDIX C

MOS SF-36 HEALTH SURVEY

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(Circle one)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

Additional Comments:

2. Compared to one year ago, how would you rate your health in general now?

(Circle one)

Much better that one year ago	1
Somewhat better than one year ago	2
About the same as one year ago	3
Somewhat worse than one year ago	4
Much worse than one year ago	5

Additional Comments:

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
I. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

Additional Comments:

4. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?

(Circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra efforts)	1	2

Additional Comments:

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	YES	NO
a. Cut down the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

Additional Comments:

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

	(Circle one)
Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

Additional Comments:

7. How much bodily pain have you had during the past 4 months?

	(Circle one)
None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very Severe	6

Additional Comments:

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

	(Circle one)
Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

Additional Comments:

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down ir the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy	1	2	3	4	5	6
I. Did you feel tired?	1	2	3	4	5	6

Additional Comments:

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

	(Circle one)
All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

Additional Comments:

11. How TRUE or FALSE is each of the following statements to you?

(Circle one number on each line)

	Definitely TRUE	Mostly TRUE	Don't Know	Mostly FALSE	Definitely FALSE
a. I seem to get sick a little easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

Additional Comments: