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Psychological Aspects of Ventilator Dependent Children

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Psychological Aspects of Ventilator Dependent Children

By

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the requirements of the degree of
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Each person whose signature appears below certifies that this thesis in his/her opinion is adequate, in scope and quality, as a thesis for the degree of Master of Arts.

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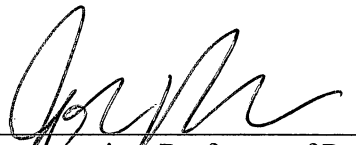

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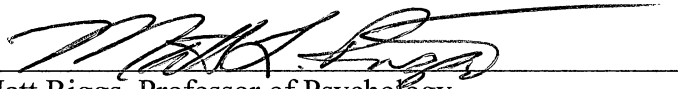

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ABSTRACT OF THE THESIS

Psychological Aspects of Ventilator Dependent Children

By

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Dr. Kiti Freier, Chairperson

Rapid advances in medicine and technology have meant more medically invasive procedures as well as the survival of more individuals who are more immanently faced with death. Ventilator-dependent children (due to sleep apnea, neuromuscular disease, and acute physical injury) make up one such group of individuals. The current study assessed a group of home-based, ventilator-dependent children for symptoms of depression and posttraumatic stress. It was found that there was a negative correlation between the child's level of depression and the amount of time per day that the child was on the ventilator. There was also a negative correlation with the level of posttraumatic stress and the percentage of life that the child had been on the ventilator and a negative correlation with the level of depression and the percentage of life that the child was on the ventilator. There was a positive correlation with the primary caregivers amount of stress and levels of both depression and posttraumatic stress in the child. It was also found that a significant percentage of the subjects were ventilator dependent with sleep apnea and were extremely obese. This study demonstrates the need to address issues related to child emotional adjustment, parental stress levels, and childhood obesity in ventilator dependent children.

Introduction and Literature Review

Since the 1970's there has been a substantial reduction of the morbidity and mortality resulting from specific diseases that has resulted in a large group of individuals who are dependent upon life-support devices such as ventilators (Goldberg, Faure, Vaughn, Snarski, & Seleny 1984; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990). As medicine evolves, however measures used to save lives are frequently invasive. Children are particularly vulnerable and helpless when it comes to medically invasive procedures due to their lack of independence and developmentally limited understanding of their medical situation.

Feelings of vulnerability and helplessness are central to contemporary understandings of depression and posttraumatic stress. It has been reported that between 0.4% and 8.3% of children and adolescents experience depression (Birmaher et al., 1996). The prevalence of depression among boys and girls is estimated to be a two to one ratio with girls being twice as likely to exhibit signs of depression than boys (Birmaher et al., 1996). Although no prevalence rates for posttraumatic stress in children were found in the literature, Pfefferbaum (1997) has reported a rate of 6% for adolescents. There is no consistent evidence in the literature that suggests any gender bias in posttraumatic stress.

Ventilator dependent children are at risk of experiencing feelings of vulnerability, fear, and helplessness. They are dependent on their caregivers for assistance in daily living. They rely on their caregivers to help with the maintenance of their ventilators as well as responding to any alarms or malfunctions that may occur. Without the aid of the caregivers, ventilator dependent children would be unable to sustain life. Further, if the

procedures are incorrectly carried out, they have the potential to end the life, or cause significant discomfort for the ventilator dependent child.

Three primary groups of children that are chronically ventilator dependent include individuals with sleep apnea, neuromuscular disease, and individuals who have experienced an acute physical injury. All of these children depend on a ventilator to sustain life whether it is for a minimum of eight hours a day or a full 24 continuous hours. There are problems that may arise when using ventilators that can endanger the child's life such as accidental disconnection or mechanical problems with the maintenance of the ventilator (Gilgoff, Peng, & Keens, 1992; Janowski, 1984). While it is expected that these situations can cause a great deal of fear and anxiety, there is no literature on this impact topic. Further, it is easy to suppose that ventilator dependent children are at risk for symptoms of posttraumatic stress and depression.

Children can be very resilient, but they can also be very helpless in situations of trauma or stress. Some ventilator dependent children may habituate to their helplessness and dependency while others may exhibit a great deal of depression, stress, anger, anxiety, or other psychological effects. It is the purpose of this study to assess if ventilator use, in particular, length of time and percentage of use, and the level of parental or primary caregiver stress, in a population of ventilator-dependent children, are associated with posttraumatic stress and depression symptoms in the child.

Ventilator Dependency

During the 1960s mechanical ventilation was introduced as an aid in intensive care units to assist acute life-threatening illnesses. It was during the 1970s that home

mechanical ventilation became an option as a cost-effective way to manage patients that required long-term care (Young, Grainger, Perkin, & Hilton, 2000). It has been estimated that in the United States there are more than 14,000 individuals requiring home mechanical ventilation (Sevick & Braham, 1997). It was not until 1985 that the US legislation officially defined ventilator dependency (Mallory & Stillwell, 1991). The legislation defined ventilator-dependents as individuals who require a ventilator at least six hours per day in order to sustain life. They must also have been on ventilator technology for at least one month in a hospital or a skilled nursing facility. If respiratory services are unavailable in the home, than the individual is confined to a medical institution such as a hospital or medically assisted living center. Without the use of ventilators, these individuals would experience respiratory failure.

Ventilator-dependent children are a growing population and unfortunately a much-understudied group of individuals in terms of their psychological sequelae. There are numerous sources in the literature relating to cost-effectiveness and the needs of the caregivers, however the actual ventilator-assisted child has gone relatively unnoticed in the research. There have been only a couple of studies that have noted the importance of understanding the ventilator-dependent child or adult's psychological state, particularly in reference to depression, anxiety, anger, and restrictive feelings (Mallory & Stillwell, 1991; Young et al., 2000).

There are some significant issues involved in ventilator dependency regardless of whether the individual is a child or an adult. Sevick, Sereika, Matthews, Zucconi, Wielobob, Puczynski, Ahmad, and Barsh (1994) have noted that these patients require a

large amount of assistance on many if not all activities of daily living, many requiring total care. They have also reported that primary caregivers spend an average of 8.4 hours a day caring for the ventilator dependent child or adult. Reviews such as Mallory and Stillwell's (1991) have shown that the restriction on mobility and the constant need of care along with body image problems are inevitably chronic problems with children who are ventilator dependent. Another problem that may arise in this population is the fear of being disconnected from their ventilator, because of the immanent possibility of suffocation and death. There have been several studies and case reports that have mentioned the inadequacy of the ventilation or the accidental situations when patients were mistakenly disconnected (Gilgoff, Peng, & Keens, 1992; Janowski, 1984). Through these ventilator experiences and clinical visits, children have been exposed to the concerns about mechanical problems and accidents that may occur with a ventilator. Many have heard of and seen other children die from complications with his or her ventilator. They are made fully aware of complications that may turn into an emergency. These children live with the stress of knowing that small complications may turn deadly for them.

There are other events that are associated with ventilator-dependency which may arouse anxiety and depression. Warzak, Engel, Bischoff, and Stefans (1991) have explained that in order to stay current with the maintenance of ventilators, individuals must undergo brief periods of time (5-10 seconds) during which time they are unable to breathe due to the removal of the ventilator. This process has been shown to cause anxiety and fear in children which may not habituate over time. Also, suctioning

procedures and the sounds of the machinery may cause anxiety and stress in ventilator dependent child (Clark, K., 1986). Dalton and Kirkhart (1985) talk about the psychosocial difficulty for children to reintegrate with their peers and feel accepted by their peers rather than feel like an outsider after becoming ventilator dependent. They note that children and adolescents may become depressed, withdrawn, or possibly aggressive to compensate for their feelings of inadequacy. Posttraumatic distress has been noted in children who experience significant trauma and Gavin and Roesler (1997) demonstrate that ventilator-dependent children may feel terror, helplessness, and the threat of death while they are being intubated, which is a process that the majority of ventilator dependent individuals must experience at some time. Another problem that may occur is if a child may be reacting to his or her parent or primary caregivers stress, which may result in a heightened amount of stress for the child. Due to these possibilities, it is apparent that ventilator-dependent individuals experience not only medical problems, but psychological problems as well.

Disorders Requiring Ventilator Dependency

Though not the only ones, there are three primary categories of disorders that frequently require ventilator dependency. These disorders include sleep apneas, neuromuscular diseases, and acute physical injury. Ventilator dependency occurs when an individual, child or adult requires mechanical assistance to breathe. Without this support the patient would die. The ventilator may be an invasive ventilator which requires surgery or a tracheostomy to hook up the ventilation unit or a non-invasive ventilator which hooks up as a mask to the nose or mouth area. In either case, a child that

requires ventilator support also requires a caregiver to help with the maintenance of the machinery and their care.

Sleep Apnea

Sleep apnea has been classified as an intermittent cessation of airflow at the nose or mouth during time of sleep according to Phillipson (1998). Phillipson (1998) asserts that apneas must be at least 10 seconds in duration to be considered significant; however, in most patients, apneas range anywhere from 20 seconds to three minutes. There are three different types of sleep apnea: Central, Obstructive, and Mixed. Central sleep apnea is characterized by the lack of ventilatory effort during an apneic episode. Obstructive sleep apnea is exhibited when an individual is trying to breathe, but the upper airway is closed off. Finally, mixed apnea is a combination of characteristics of central and obstructive sleep apnea (Helfaer & Wilson, 1994; Tierney, McPhee, & Papadakis, 2000).

Research shows that mechanical ventilation reduces the frequency and severity of damage (particularly to the brain) caused by the oxygen loss associated with apneic episodes (Henderson & Strollo, 1999). There are many different types of ventilator remedies that are used in a hospital setting as well as at home. With the help of these innovations, it has been reported that sleep apneics are able to be more fully functioning and improve daytime alertness (Henderson & Strollo, 1999). Apneic episodes have been known to be the cause of death among children and adults (Yantis, 1999). Relationships between obstructive sleep apnea and sudden infant death syndrome is not uncommon,

reports Yantis (1999). She has also reported that obstructive sleep apnea affects between one to two percent of all children from infancy to adolescence.

Neuromuscular Disease

Neuromuscular disease is a very broad term that encompasses a number of different specific diseases which may include muscular disorders, motor neuron diseases, neuromuscular junction diseases, peripheral nervous system diseases, and a number of other disorders, syndromes, and diseases. It has been demonstrated that neuromuscular diseases cause disturbances in muscle and nerve units that usually result in the impairment of the efferent nervous system, causing individuals to breathe improperly or not at all without assistance (Brooke, 1986).

Depending on the disease, ventilator support may be needed soon after birth, or in cases such as Duchenne muscular dystrophy, ventilator assistance may not be required until late adolescence (Mallory & Stillwell, 1991). Eventually all individuals with a neuromuscular disease will need chronic ventilator assistance rather than intermittent use. As Kelly and Luce (1991) report, it is a common occurrence for neuromuscular diseases to negatively affect respiratory muscles and cause them to quit working which in turn leads to the need for chronic ventilator support or even death.

Acute Physical Injury

For the purpose of this discussion, the focus will be on spinal cord injury, resulting in quadriplegia, as this is the only acute physical injury which has been found in the literature to result in the dependence of a ventilator. This type of injury involves phrenic nerves at the C3 to C5 level of the spinal cord and causes muscle paralysis that

inhibits the individual from being able to breathe on his or her own. Paralysis of the intercostal and abdominal muscles inhibit inspiration and expiration of one's breath (Kelly & Luce, 1991). Due to the paralysis of these muscles, most individuals with acute spinal cord injuries will suffer ventilator dependency according to Kelly and Luce (1991) and Mallory and Stillwell (1991).

Family Stress

It has been found that children and parents respond to one another's stress (Foy, Madvig, Pynoos, & Camilleri, 1996; Pfefferbaum, 1997). In family stress theory, it is suggested that stressors and strains have a direct and indirect effect on how adolescents develop and adapt to his or her situation (Hamilton, McCubbin, Needle, & Wilson, 1985). Hamilton, McCubbin, and Patterson (1983) explain that in family stress theory, it is stressor events or hardships that cause tension in a family and lead to family stress. They define family stress as a state that is caused by either an actual or perceived demand/capability imbalance in the family system and demands a restructuring of the family functions. Family stress theory is based on the idea that families, as a whole, share meanings about specific stressful events, family identity, and their view of the world (Patterson & Garwick, 1994). It has been shown that major stressful life events, particularly ones that imply chronic hardships, cause a crisis in families that may cause reorganization of the families style of functioning, according to Patterson and Garwick (1994). A child with a chronic situation such as sleep apnea, neuromuscular disease, or an acute physical injury may cause a family to readjust and reorganize the families style

of functioning. In turn, this may cause stress by added demands on family members, change of routine, roles and expectation (Patterson & Garwick, 1994).

After looking at a group of school aged children who had been ventilator dependent during the neonatal stage of their life, Gunn, Lepore, and Outerbridge (1983) found that parents that are in contact with critically ill infants experience high levels of stress and anxiety which have demonstrated long term effects on parent-child relationships. After a highly public and traumatic boating accident, Martini, Ryan, Nakayama, and Ramenofsky (1990) looked at some psychiatric issues surrounding traumatic injury. They found that if a child witnesses an appropriate response from his or her family members in regards to his or her injury, then the child will have a higher chance of tolerating the stressful event. In a study that looked at the psychosocial impact of pediatric heart transplantation it was found that stress, resources, and coping were very strong indicators of how a child dealt with the transplantation (Uzark, Sauer, Lawrence, Miller, Addonizio, and Crowley, (1992). Although the heart transplant children did not differ from other peers on self-concept and anxiety, they did have a lower level of social competence and exhibited more behavioral problems. The behavioral problems however, were large indicators of higher levels of depression and were associated with higher levels of family stress and the lack of ability or resources to deal with stress. From the presented literature, it may be reasonable to suspect that children who are ventilator dependent may react to his or her parents stress and the reorganization of the family unit.

There are many stressors that are present when a ventilator dependent child or adult is in a home ventilator program. The patient may experience a variety of fears and

stresses. Some of these stressors may include the need to keep up with the complicated planning of care, the need to be tied to a machine to sustain life, upper respiratory infections which may lead to isolation and restriction of activities, not being able to reach what they felt was their full potential, uncertainties of the ventilator and dealing with friends who are not familiar with it, and increased loneliness (Miller, Colbert, & Schock, 1988). Not only does the patient exhibit stress, but the family does as well. Miller, Colbert, & Schock (1988) continue to explain some of the stressors that effect the family of a ventilator dependent child or adult. These stressors may include feeling that they must be tied to places where they can take care of the patient and not being able to stray from home, the frustration of not being able to plan ahead due to the uncertainty of the patient, having to provide continuous care, having less time available for other family members or friends, constant accommodations needing to be made, care of respiratory infections and problems with the ventilator, the presence of overnight care providers in their home, and thinking about the future.

Depression

Depression is classified under what the American Psychiatric Association (in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, DSM-IV) refers to as a Mood Disorder. The diagnosis is the same for children as it is for adults unless otherwise stated. The main feature of Mood Disorders is that one's disposition negatively affects one's mood. The DSM-IV (1994) explains that a Major Depressive Disorder includes one or more Major Depressive Episodes that lasts for at least two weeks and is accompanied by at least four more of the symptoms for depression.

Dysthymic Disorder includes at least one year (for children) of a depressed mood where there are more depressive days than not, and it must be accompanied by additional depressive symptoms that do not fit into Major Depressive Disorder.

According to the DSM-IV (1994), a Major Depressive Episode would include a depressed mood which may be demonstrated through irritability rather than sadness in children or adolescents or a loss of interest of pleasure in most activities for at least two weeks. To be considered an episode, one must exhibit at least four of the following symptoms as well: A change in appetite; weight loss or gain; trouble with normal sleep patterns; changes in psychomotor activity; lowered energy; hopelessness; self pity; weepiness; negative evaluation of one's worth; difficulty with thinking, concentrating, or making decisions; or recurrent thoughts of death or suicidal tendencies (Hersen & Ammerman, 1995; Janzen & Saklofske, 1991). Carlson & Kashani, (1998); Kolvin et al. (1991); and Mitchell et al. (1988) have all suggested that symptoms of separation anxiety, phobias, somatic complaints, and behavioral problems occur frequently in children with depression.

By the age of 18 approximately 20% of the United State's youth will have experienced a depressive episode with the occurrence slightly higher in females than in males (Tompson, McNeil, Rea, & Asarnow, 2000). Though the rate of clinical depression is lower, it is still a significant problem among children and adolescents. Actual clinical depression is found in between .4% - 2.5% among children and between .4% - 8.3% in adolescents (Birmaher et al, 1996).

Depression has been shown to be highly associated with anxiety disorders which includes posttraumatic stress disorder (Birmaher et al., 1996; Cohen, 1998; DSM-IV, 1994; Hersen & Ammerman, 1995; Janzen & Saklofske, 1991; Laurent & Landau, 1993; Pfefferbaum, 1997). However, as Clark and Watson (1991) have noted, the loss of pleasure or lack of positive affectivity and other symptoms of melancholia are unique to depression. Other situations that have been linked with depressive symptoms are stressful events in one's life (Birmaher et al., 1996; Janzen & Saklofske, 1991). These events would include loss, lack of support, lack of control over one's life, and bereavement as well as the inability to cope with stress.

Depression and Medical Settings

It has been well documented that children in hospital settings, and children who are suffering from physical diseases express emotional distress including symptoms of depression, irritability, withdrawal, and anxiety (Diaz de Carvalho et al., 1998; Rodriguez and Boggs, 1998). It has been reported by Rodriguez and Boggs (1998) that up to 40% of children in a pediatric setting exhibit depressive symptoms. Another study by Yap, which was reported by Rodriguez and Boggs (1998), estimated that 20% of medically ill children experience emotional as well as behavioral problems.

Based on the above research it seems reasonable to expect to find that a significant number of individuals who are ventilator-dependent because of sleep apnea, neuromuscular disease, or acute physical injury will show significant levels of depression.

Depression and Sleep Apnea

The literature on sleep apneics and depression is also very limited. Bliwise, Yesavage, Sink, Widroow, and Dement (1986) conducted a study on depressive symptoms in individuals who experienced problematic respiration during sleep in which they found that sleep-related respiratory disturbance is related to depressive symptoms. Kales, Caldwell, and Cadieux (1985) found that 56% of the individuals that were ventilator-dependent due to sleep apnea presented with depressive symptoms. These studies demonstrate that there is reason to believe depression and sleep apnea are correlated. Again, the child population appears to be largely understudied in this area.

Depression and Neuromuscular Disease

Though the literature on depressive symptoms in neuromuscular disease is extremely limited. In a review article, Hilton, Orr, Perkin, and Ashwal (1993) stated that neuromuscular diseased children with Duchenne Muscular Dystrophy experience many emotional problems. According to their review of the literature the most prevalent emotional problems are depression and anxiety. This article was in response to ten years of experience with these individuals at Loma Linda University Medical Center. Further research is needed to confirm these psychological problems. This initial review suggests that these children may benefit from psychological interventions as well as medical.

Depression and Acute Physical Injury

In a study done by Tate, Forchheimer, Maynard, and Dijkers (1994), individuals who experienced spinal cord injuries were assessed for the effects of being handicapped, on depression and emotional distress after being discharged from rehabilitation. They

note that individuals who experience physical disability, experience higher levels, and more severe signs, of depression than individuals with depression that do not experience a physical disability. The results of this study showed a high correlation between depression/distress and handicap. The greater the handicap, the greater the restrictions are in one's social environment and the higher the level of depression exhibited. In another study on spinal cord injury there was a 33% - 60% prevalence rate of depression, sleep disturbance, suicidal ideation, and guilt with no significant differences between paraplegics and quadriplegics (Dias de Carvalho, Andrade, Tavares, & Sarmento de Freitas, 1998). The term reactive depression has been suggested to describe the psychological reaction to psychosocial stressors caused by the acquisition of a disability by Tate et al. (1994). Unfortunately, the child population has been largely understudied for this particular type of injury.

Posttraumatic Stress

Posttraumatic Stress Disorder is classified as an anxiety disorder in the DSM-IV (1994). Though the specific diagnostic criteria are re-experiencing a severely traumatic event along with demonstrating symptoms of increased arousal and avoidance of stimuli which is associated with the trauma. Posttraumatic stress is a result of an exposure to an extremely traumatic event that involves direct personal threat of death or threat to an individual's personal integrity (DSM-IV, 1994). As a response to the event, an individual may respond with intense fear or helplessness, which may involve disorganized or agitated behavior. An individual experiencing posttraumatic stress may exhibit signs of increased arousal, anger, anxiety, and dissociation. They may feel detached or avoid

feelings and thoughts of the trauma. For children, re-experiencing an event may include frightening dreams with reference to the event (DSM-IV, 1994; Matsakis, 1994). The effects of traumatic stress are sometimes categorized as cognitive, affective, behavioral, or somatic-physiological according to Richards and Bates (1997).

When adolescents are exposed to prolonged or repeated stressors, their symptoms may consist predominantly of dissociative features and angry or aggressive outbursts according to Goodwin, Hornstein and Terr (as cited in Cohen, 1998). It has been found that the amount of trauma response correlates with the amount of exposure, whether the exposure involves emotional or physical closeness (Pfefferbaum, 1997). It may be important to note that children and parents respond to one another's stress (Foy et al., 1996; Pfefferbaum, 1997); therefore, if a ventilator-dependent child's parents are not coping with the demand of care for their child and experience a sense of helplessness due to their childs' life threatening trauma (Gavin and Roesler, 1997), the child may be reacting to his or her parents stress.

Posttraumatic stress symptoms may be different depending on what age group one is looking at (Pfefferbaum, 1997; Cohen, 1998; Wintgens, Boileau, & Robaey, 1997). For example, elementary children experience nightmares, preoccupation with the event, excessive fear, psychosomatic complaints, and hyperarousal. Adolescents, on the other hand may experience some of these same symptoms, but may exhibit very withdrawn and compliant behavior, or at the other extreme may become very aggressive in nature. Wintgens, Boileau, and Robaey (1997) also made a distinction between the experience of a one-time traumatic event and a prolonged, long-standing, or repeated traumatic events.

It appears that prolonged, long-standing or repeated traumatic events produce posttraumatic stress symptoms in a large proportion of children.

There is reason to believe that childhood trauma is particularly important and impactful. Uncontrollable and frightening experiences may have their most profound effect during childhood years due to the fact that the central nervous system and cognitive functions are not yet fully developed (Armsworth & Holaday, 1993). Therefore, it is reasonable to conclude that these traumatic events may cause long lasting effects if not dealt with and treated adequately.

Posttraumatic Stress and Sleep Apnea

Youakim, Doghramji, and Schutte (1998) concluded that sleep deprivation and daytime somnolence, which are symptoms of sleep apnea, may cause individuals to be susceptible to posttraumatic flashbacks or other anxiety symptoms. Because of the lack of data with this particular population, it would be important to address points in this particular group of children.

Posttraumatic Stress and Neuromuscular Disease

There was no literature found on posttraumatic stress and neuromuscular disease. This area begs for research and interventions for these children. Because of the threat of death and the helplessness due to the nature of neuromuscular disease, it seems reasonable that posttraumatic stress is a significant factor for these children.

Posttraumatic Stress and Acute Physical Injury

It has been demonstrated that many people experience psychological trauma after injury. It has been difficult to distinguish whether or not psychological distress after an

event is a result of the trauma itself or a pretrauma variable (Pobert, Bisson, & Shepard, 2000). In a recent study by Aaron, Zaglul, and Emery (1999) posttraumatic stress disorder was assessed in children following acute physical injury. The measures that were used in this study were a narrative account, the Reaction Index and Impact of Events Scale. It was found that out of the forty children interviewed one month after his or her trauma, 22.5% of them met DSM-IV (1994) criteria for posttraumatic stress disorder (all 3 symptom clusters, which includes intrusive recollections; avoidant/numbing symptoms; and hyper arousal symptoms (Schelling et al., 1998)) while 47.5% of them met two of the three DSM-IV (1994) clusters. Based upon their study, the authors propose a model of posttraumatic stress disorder symptom development. In its simple form, the model suggests that the child's fear and perception of threat to life during the traumatic event create the situation which places the child at risk for posttraumatic stress disorder. Those children who suppress affect and thoughts about the event increase the risk of developing posttraumatic stress disorder. Children who actively think about their experience exhibit less severe symptoms. The results of this study suggest that children who are experiencing or have experienced physical injury may be suffering from psychological distress and may benefit from psychological as well as medical intervention.

In a study on adult veterans, conducted by Binks, Radnitz, Moran, and Vinciguerra (1997) it was found that the higher the spinal cord injury, the fewer posttraumatic stress symptoms were displayed as measured by the Clinician Administered PTSD Scale. They believe that this fits with the literature supporting the

idea that the peripheral nervous system has a role in posttraumatic stress symptoms. Another study that dealt with spinal cord injury compared veterans with posttraumatic stress disorder with and without spinal cord injury (Radnitz et al., 1998). This study supported the idea of the peripheral nervous system playing a part in posttraumatic stress when they found that quadriplegics exhibited fewer signs of posttraumatic stress than a control group of individuals without spinal cord injury. This may suggest that the higher the spinal cord injury occurs, the less the nervous system is able to respond to the trauma.

Rationale for Current Research

As the lack of literature demonstrates, ventilator dependent children are a highly understudied population. The psychological ramifications due to the fear, anxiety, feelings of impending death, and helplessness that ventilator dependent children may experience, all lend themselves to contributing to the development of depression and posttraumatic stress. As a result, it was hypothesized that:

1. There would be a positive correlation with the level of posttraumatic stress and depression for these children and the amount of time per day that the child is on the ventilator.
2. There would be a positive correlation with the level of posttraumatic stress and depression and the percentage of life that the child has been on the ventilator.
3. There would be a positive correlation with the level of posttraumatic stress and depression with the amount of the primary caregivers level of stress.

4. There would be a negative correlation with children that have experienced an acute physical injury with the level of posttraumatic stress and depression and the severity of the injury based on the level of breakage in the spine.

Method

Participants

Participants included six male and three female children, ages eight to sixteen and their primary caregivers, from the Home Mechanical Ventilation Program at Loma Linda University Medical Center. The age group for these children was selected so that all participants would be in similar developmental stages and allow for the use of appropriate standardized measures available for depression and posttraumatic stress. Involvement was on a voluntary basis with consent from the parents and assent from the child (see appendix B & C). All children were medically diagnosed with either sleep apnea, neuromuscular disease, or had suffered an acute physical injury that required the individual to be ventilator dependent, for at least six hours per day, in order to sustain life. The individuals also had to pass an initial screener used to assure verbal and intellectual understanding of the measures used.

Measures

Peabody Picture Vocabulary Test – Third Edition

The Peabody Picture Vocabulary Test – 3rd Ed. (PPVT-III) (Dunn & Dunn, 1997) is a test to give an estimate of an individual's verbal ability or scholastic aptitude. This test is for English speaking individuals between the ages of 2 ½ through 90+ years. It takes approximately 11 to 12 minutes to administer. A template with four pictures is presented to the examinee while the examiner reads and word and the examinee chooses the best picture which represents the word that the examiner read. Alternate-forms reliability coefficients are reported to be between .93 and .95 for the age range of eight to twelve. Alpha and split-half reliability were reported to be between .92 and .96 for the

age range of eight to twelve. Validity has been supported throughout the literature. Criterion validity has been demonstrated through three studies in particularly. The PPVT-III was correlated with the Wechsler Intelligence Scale for children-Third Edition. The correlations between the standard scores of the two tests ranged from .82 to .92. The standard scores of the PPVT-III correlated with the Kaufman Adolescent and Adult Intelligence Test with correlations ranging from .76 to .91. The standard scores of the PPVT-III correlated with the Oral and Written Language Scales with correlations ranging from .63 to .83.

Trauma Symptoms Checklist for Children – Alternate

The Trauma Symptoms Checklist for Children-Alternate (TSCC-A) (Briere, 1996) is a 44-item self-report measure with each item rated on a four point continuum with the number one equaling "never" and the number four equaling "almost all of the time" (Sauter & Franklin, 1998). The measurement scale includes validity scales for measuring Underresponse and Hyperresponse with five clinical scales including Anxiety, Depression, Anger, Posttraumatic Stress, and Dissociation (Briere, 1996). This measure reports high internal consistency scores for Underresponse, Hyperresponse, Anxiety, Depression, Anger, Posttraumatic Stress and Dissociation with alpha's .85, .66, .82, .86, .89, .87, and .83 respectively. It exhibits face validity along with convergent validity showing positive correlations with Youth and Parent report versions of the Child Behavior Checklist. Discriminate validity was shown with the Children's Depression Inventory with the exception of the Depression scale which showed convergent validity with a .73 correlation. Construct validity was shown by comparing a normative sample

and a sample taken from child abuse and trauma centers which shows that scale scores are higher in samples of children with histories of stressful or traumatic events, increase in presence of more severe trauma, and decrease in the response to therapeutic interventions that are used to resolve trauma related distress. Predictive validity was demonstrated as well (Briere, 1996).

Children's Depression Inventory

The Children's Depression Inventory (CDI) (Kovacs, 1992) measures depressive symptoms in children and adolescents between the ages of 8 and 17. It is a self-report instrument consisting of 27 items each consisting of a set of three statements of which the individual checks the one that they feel pertains the most to them. The factors that are measured include Negative Mood, Interpersonal Problems, Ineffectiveness, Anhodenia, and Negative self-esteem with an overall score for level of depression. The Children's Depression Inventory demonstrates good internal consistency with coefficients ranging from various groups of samples of .71 to .89. In looking at the individual factors, the internal consistency varied from .59 to .68 which is acceptable for short factor subscales. The test-retest reliability is considered to be at an acceptable level of stability though it should be noted that this test is designed to measure states and not traits. The Children's Depression Inventory has been shown to exhibit face validity. Criterion and construct validity were shown by examining the relationship between the Children's Depression Inventory and independent psychiatric diagnoses with results showing that patients with higher self-rated depression received higher global severity ratings of depression on the basis of a semistructured interviews. The mean scores clinical and non-clinical

populations differed by 2.73 points, with the non-clinical group averaging an 8.54 and the clinical group averaging an 11.18. Concurrent validity was determined against two self-rating instruments that assess constructs related to depression. Convergent and discriminate validity was demonstrated when the Children's Depression Inventory positively correlated with scores from the Revised Children's Manifest Anxiety Scale ($r = .78$) and negatively with the Coopersmith Self-Esteem Inventory ($p = .0006$) (Kovacs, 1992).

Parenting Stress Index

The Parenting Stress Index (PSI) (Abidin, 1983) measures the levels of stress that a parent is going through while their child is between 1 month and 12 years of age. The measure was created in response to the need of optimizing a child's emotional development. The measure has three principle components including child characteristics, parent characteristics, and situational/demographic life stress. This measure consists of 120 self-report statements and questions with some answers rated on a five point continuum from strongly agree to strongly disagree or a numbered continuum of 1 through 5, and 19 yes or no questions. The factors of stress that are measured are distractibility/hyperactivity, adaptability, reinforces parent, demandingness, mood, acceptability, competence, isolation, attachment, health, role restriction, depression, spouse, and life stress. For the purpose of the current research, the overall life stress score was used in the correlations. The life stress score shows how high a parents stress level is due to situational circumstances that are out of their control. The Parenting Stress Index exhibits high internal consistency with the reliability between the child domain,

parent domain, and total stress scale being .90 or greater. The test-retest reliability is also high. In a clinical sample of 30 mothers visiting their childs pediatrician, the reliability was .96 for the total stress score. In another sample with 15 mothers visiting a pediatric clinic, the total stress reliability was .88 over a 3-month period. Validity has been demonstrated in a large number of different populations ranging from individuals with apnea, cystic fibrosis, traumatic injury, divorcee's, children with behavioral problems, disability and illness problems, and a range of abuse. Correlations with measures such as the Beck Depression Inventory, Child Behavior Scale, Family Adaptability and Cohesion Evaluation Scales, Family Impact Questionnaire, and Parent Locus of Control are also demonstrated (Abidin, 1983).

Demographic Questionnaires

A questionnaire was used to assess the demographics of the individuals and their situation. Both the parent (see Appendix D) and the child (see Appendix E) filled out a questionnaire. The parent questionnaire asked questions regarding the etiology of the ventilator and specifics regarding the care of the child. The child questionnaire asked questions regarding feelings such as their fear of being disconnected from the ventilator and who they trusted to take care of them the most.

Procedures

The coordinator of the program contacted each eligible family for permission of the researcher to contact them. Following this initial contact, all consenting parents whose child met the inclusion criteria were contacted by telephone by the researcher (see appendix A). If the parent was willing to participate in the study, an appointment was

made to sign the consent form (see appendix B) and begin the assessment. All assessments were scheduled during a routine scheduled appointment at the Home Ventilation Program at the Family Medical Offices in Loma Linda, California. The examiner administered the Peabody Picture Vocabulary Test 3rd Edition to screen for verbal capability. If the individual did not exhibit average verbal capability defined as an age equivalency of eight or above, the individual was eliminated from the study. Each individual was given the Trauma Symptoms Checklist for Children—Alternate followed by the Children's Depression Inventory and a set of questions regarding the child's experience while ventilator dependent (see appendix E). These inventories were read to the children and filled out in the presence of the researcher. The full battery of tests took approximately forty-five minutes. While the child was being assessed, the primary caregivers of the individual patients were asked to fill out a demographic questionnaire (see appendix D) along with the Parenting Stress Index in the waiting room. Medical information regarding the child's BMI was obtained from the medical record.

After the child and the caregiver filled out the measures, the examiner debriefed the child and primary caregiver in the assessment room. At this time any questions from the caregiver or child were addressed. The examiner provided information to each parent on how to contact her in order to find out the results of the study (see appendix F). The caregiver was also given information on how to contact further psychological assistance for them or their child (see appendix F).

RESULTS

Subjects

After a case review by the program coordinator of all children who are a part of the Loma Linda University Medical Center's Pediatric Mechanical Home Ventilation Program, a total of 16 subjects who were between the ages of 8 and 16 and were ventilator dependent due to sleep apnea, neuromuscular disease, or an acute physical injury, met inclusion criteria for the research study. One parent would not allow her child to be tested due to personal opinions regarding psychologists. One child was not included because they were the only Spanish-speaking child in the sample. One child did not cooperate with the assessment and was unable to complete the interview due to behavioral problems. As a result, 13 subjects were tested. In order to screen for verbal ability, each child was given the Peabody Picture Vocabulary Test – third edition (PPVT-III). A prerequisite of having an average verbal ability of 85 or above had been set in order for the child's protocol to be used in the data analyses. However, seven of these children had a verbal ability that was below 85 according to the PPVT-III. Thus, the sample size would have been six. In order to limit sample reduction, subjects were chosen according to an age equivalency scale to assure that the child would be able to respond to all of the questionnaires, which were normed for ages eight and above. After verifying age equivalencies of verbal ability, and excluding children who were not at an eight-year-old level or above, the total sample size included nine subjects.

Screening the data

The data was screened for missing data and accuracy of data entry. It was concluded that each subject had responded to all questionnaires and would be included in

all of the analyses. In order to assure appropriateness for parametric analysis, the data was screened for outliers. Using a criterion of three standard deviations from the mean, it was found that there were no outliers. When viewing histograms for the variables, it was found that the hours per day a child is on a ventilator, percentage of life a child is on a ventilator, age equivalency for the PPVT, CDI total, CDI interpersonal problems, CDI ineffectiveness, CDI anhedonia, CDI negative self esteem, TSCC-A anxiety, TSCC-A anger, and the BMI scores all had a slight positive skew. However, due to the limited sample size and clinical population, it was expected that there would be the possibility of some skewed data. Thus, all data was considered adequate for this study.

Descriptive Variables

The sample consisted of six males and three females. The ethnic make up of the group included six Hispanics, two Caucasians, and one Asian. Five children were ventilator dependent due to sleep apnea, two due to an acute physical injury, and two due to a neuromuscular disease. The majority of the subjects then were males, Hispanics, and ventilator dependent due to sleep apnea. Table 1 refers to these demographics.

Table 1

Demographics

Gender	#
Males	6
Females	3
Total	9
Ethnicity	#
Hispanic	6
Caucasian	2
Asian	1
Total	9
Reason for ventilation	#
Sleep apnea	5
Neuromuscular disease	2
Acute physical injury	2
Total	9

Table two provides the means and standard deviations of the subject's age, verbal ability, age equivalency, hours per day they spent on the ventilator, and the percentage of life (calculated using months) that they were on a ventilator. No Mean or Standard Deviation was given for the level of spinal cord breakage due to the fact that there were only two children who had a spinal cord injury and each child exhibited a break in the C1 to C2 level of the spine; therefore, there was no variance in the level of the spinal cord injury.

Table 2

Patient presentation

	Mean	Standard Deviation
Age	12.9	2.57
Verbal ability	94	13.38
Age equivalency	12.4	4.6
Hours/day on ventilator	12.3	6.76
Percentage of life on ventilator (Calculated by months of life)	21	26

Table 3 lists the means and standard deviations of the CDI total, TSCC-A anxiety scale, TSCC-A anger scale, TSCC-A posttraumatic stress scale, the level of fear the child is of being disconnected from his or her ventilator, and the PSI total. Table 3 also lists the normative data which was provided by each test's manual. The research sample had a lower mean on the children's overall CDI depression score, TSCC-A anger score, and on the TSCC-A level of posttraumatic stress score then the normative data. However, the standard deviation on the TSCC-A level of posttraumatic stress was higher for the research sample. The research sample also showed a higher mean for the children's TSCC-A anxiety level and PSI parental stress levels than the normative sample showed. Though, it should be noted that the majority of the research sample was of Hispanic origin and the PSI manual gives a separate norm for Hispanics.

Table 3

Study related variables

	Research sample		Normative sample	
	Mean	SD	Mean	SD
CDI total	7.89	8.45	9.98	*
TSCC-A anxiety	6.44	5.08	5.98	4.26
TSCC-A anger	5.67	5.24	8.78	6.03
TSCC-A posttraumatic stress	8.11	6.74	8.51	5.72
Fear of disconnection (scored 1-5)	2.9	1.54	N/A*	N/A*
PSI total	236.78	43.13	222.8**	36.6**

* unavailable data
**for Hispanics, M=249.9, SD=38.8

A single sample z-test was run in order to assess how much the research sample varied away from the normative sample provided in the TSCC manual. For the anxiety scale z=.32, p=.37, for the anger scale z=-1.55, p=.06, and for the posttraumatic stress scale z=-.21, p=.42. This shows that the anger scale was significantly different at the .06 level. In addition a single sample t-test was run to assess how much the sample varied from the normative sample provided in the CDI manual for the total t (8)=-.743 p=.479. These results showed that the research sample was not significantly different from the normative data.

Testing of Hypotheses

Due to the size of the sample and the lack of power that the data carried, the correlations were examined in reference to Cohen's (1992) standards for effect sizes. The data presented was examined in an explorative manner in hopes of defining future hypotheses. In line with Cohen's (1992) recommendation for effect sizes, the following

cut off points for the levels of effect sizes were utilized: .15 and below = small, .16 - .24 = small-medium, .25 – .35 = medium, .36 – .44 = medium-large, and .45 and above = large.

H1- The correlation between the level of posttraumatic stress and the amount of time per day the child was on the ventilator was r=.007. This showed that there was little to no relationship between the two variables. The correlation between the level of depression and the amount of time per day the child was on the ventilator was r=-.234. This was a small-medium effect showing that the more hours per day the child was on the ventilator, the less depressed the child was. (See table 4)

H2- The correlation between the level of posttraumatic stress and the percentage of life the child was on the ventilator was r=-.268. This showed that there was a medium relationship between the two variables, the higher percentage of life the child was on the ventilator the less posttraumatic stress the child exhibited. The correlation between the level of depression and the percentage of life the child was on the ventilator was r=-.295. The Pearson correlation reached a medium effect size which showed that the higher the percentage of life the child was on the ventilator, the less depressed the child was. (See table 4)

H3- The correlation between the level of posttraumatic stress and the amount of the primary caregivers level of stress was r=.275. This showed that there was a positive relationship, with posttraumatic stress increasing as the primary caregivers stress increased. The correlation reached a medium effect size. The correlation between the level of depression and the amount of the primary caregivers level of stress was r=.318.

This showed that as the primary caregivers level of stress went up, the child's level of depression went up. The correlation was of a medium effect. (See table 4)

H4- This analysis, which addressed levels of spinal cord injury, was unable to be performed due to the lack of variance and the limited amount of individuals with an acute physical injury, which resulted in a spinal cord breakage.

Table 4

Pearson correlations

	Hours per day	Percent of life	PSI total
TSCC-A anxiety	.045	-.190	.293*
TSCC-A anger	.031	-.214	.526***
TSCC-A pts.	.007	-.268*	.275*
CDI total	-.234	-.295*	.318*
CDI negative mood	-.056	-.166	.245
CDI interp. problems	-.191	-.319*	.141
CDI ineffectiveness	-.385**	-.319*	.445**
CDI anhedonia	-.147	-.303*	.079
CDI neg. self esteem	-.238	-.229	.477***
Fear of being disconnected	.69***	.83***	

*= Medium effect size
**= Medium-large effect size
***= Large effect size

Other findings

Pearson correlations were also performed to view if there was a relationship between hours per day on the ventilator and anxiety (r=.045), anger (r=.031), negative mood (r=-.056), interpersonal problems (r=-.191), ineffectiveness (r=-.385), anhedonia (r=-.147), and negative self-esteem (r=-.238). The correlations with anxiety, anger, negative mood, interpersonal problems, anhedonia, and negative self-esteem were all

found to have a minimal effect size. The Pearson correlation with negative self-esteem had a correlation approaching a medium effect size showing that there was a negative relationship between the CDI negative self-esteem scale and the number of hours per day the child spent on his or her ventilator. The Pearson correlation with ineffectiveness exhibited a medium-large effect. Showing that there was a negative relationship between the CDI ineffectiveness scale and the amount of hours per day the child spent on the ventilator. (See table 4)

Pearson correlations were also performed to view if there was a relationship between percentage of life on the ventilator and anxiety (r=-.190), anger (r=-.214), negative mood (r=-.166), interpersonal problems (r=-.319), ineffectiveness (r=-.319), anhedonia (r=-.303), and negative self-esteem (r=-.229). The correlations using anxiety, anger, negative mood, and negative self-esteem were all found to have small or small to medium effect sizes. The Pearson correlation with interpersonal problems, ineffectiveness, and anhedonia all exhibited a medium effect. Showing that there was a negative relationship between the CDI interpersonal problems, ineffectiveness, and anhedonia scale and the amount of hours per day the child spent on the ventilator. (See table 4)

Pearson correlations were performed to assess whether or not there was a relationship between the parenting stress inventory and anxiety (r=.293), anger (r=.526), negative mood (r=.245), interpersonal problems (r=.141), ineffectiveness (r=.445), anhedonia (r=.079), and negative self-esteem (r=.477). The correlations using interpersonal problems and anhedonia were found to have a small effect size. The

correlation using negative mood was approaching a medium effect size and the Pearson correlation utilizing anxiety reached a medium effect size. The correlation with ineffectiveness was approaching a large effect and the correlation with negative self-esteem and anger exhibited a large effect. All of the correlations showed that the higher the primary caregivers stress is, the higher the level of negative mood, anxiety, ineffectiveness, negative self-esteem, and anger in the child. (See table 4)

Finally, Pearson correlations were performed to assess the relationship between the self-report on the amount of fear the child had of being disconnected from the ventilator and the amount of time per day the child was on the ventilator and the percentage of life the child was on the ventilator. There was a large effect with the fear of disconnection and the amount of time per day on the ventilator (r=.69). This showed that the more hours per day the child was dependent on the ventilator the more fearful the child was of being disconnected from the ventilator. There was also a large effect with the fear of disconnection and the percentage of life the child had been on the ventilator (r=.83). This showed that the longer the child had been on the ventilator over their lifetime, the more fearful the child was of being disconnected from the ventilator. (See table 4)

Table 5 lists each subject and their standardized T score. Out of the nine subjects, it was found that there was one subject who exhibited clinically significant pathology in the CDI's total depression scale, TSCC-A anxiety scale, TSCC-A anger scale, and TSCC-A posttraumatic stress scale. The subject was ventilator dependent due to sleep

apnea and was grossly obese. No other subjects exhibited any clinically significant standardized T scores.

Table 5

T Scores

Subject	CDI total	TSCC-A anxiety	TSCC-A anger	TSCC-A pts.
1	37	49	40	53
2	69*	87*	64*	84*
3	41	49	40	44
4	58	47	40	49
5	41	47	54	45
6	39	46	46	49
7	51	52	39	49
8	42	49	46	41
9	41	44	38	41

* = clinically significant T score

Scatterplots were used to view the relationship between the PSI total and the CDI total, CDI ineffectiveness, CDI negative self-esteem, and the TSCC-A anger scale. Upon noting the pattern between these scatterplots, it appears that there is the possibility that low scores were able to be predicted, however, as the scores increased, it was more and more difficult to predict what the scores would be (Appendices G). Scatterplots, which looked at the percentage of life that the child was on a ventilator and the total amount of depression, anxiety, anger, and posttraumatic stress showed that there may be the opposite relationship. It may be more difficult to predict where the lower scores are, but as the scores increase, it may become easier to predict the different levels of depression, anxiety, anger, and posttraumatic stress that the individual exhibits (Appendices H). Therefore, the higher the levels of depression, anxiety, anger and posttraumatic stress

these children experienced, the easier it was to predict where they would be represented on the plot.

Scatterplots were used to view the relationship between the body mass index (BMI) of the child and the child's anxiety, anger, posttraumatic stress, and depression. It appears that the higher the child's BMI was, the higher the level of anxiety he or she experienced. Also, it appears that it may be possible that the higher the BMI, the higher the level posttraumatic stress the child experienced (Appendices I). When reviewing the BMI's of the children, the researchers found that seven of the children were obese, one child was average, and one child was underweight. According to the descriptive groups, it broke down that all children in the sleep apnea and acute physical injury group were obese, while one child with neuromuscular disease was average and the other child with neuromuscular disease was underweight.

Discussion

Children who are ventilator dependent are a significantly understudied population. Though there are a number of reasons why a child may become ventilator dependent, the current study focused on children with sleep apnea, neuromuscular disease, and acute physical injury. There has not been an organized effort in understanding these children's psychological experiences. In order for these children to reach their full potential in functioning, it is necessary that physicians and therapists who work with these children take into consideration the child's psychological experience as well as their physical experience.

This study, addressed some of the psychological factors that were thought to pertain to children who are ventilator dependent. It was proposed that there would be a positive correlation with both the child's level of posttraumatic stress and the child's level of depression and the amount of time per day that the child was on the ventilator. However, in this study, the number of hours the child was on the ventilator was not significantly related to how much posttraumatic stress the child acknowledged. The correlation with depression was negative, with a small-medium effect size, thus opposite to what was expected, the more the child was on the ventilator, the lower the level of depression the child reported. Children who were on the ventilator for less hours per day may report higher levels of depression because being hooked up and unhooked from the ventilator was a consistent and conscious reality of dependence for that child at least once a day, while a child who was on the ventilator 24 hours a day may not have the same daily reminder and conscious reality.

This is also substantiated by the second hypothesis that posited that there would be a positive correlation with the level of posttraumatic stress and the percentage of life the child had been ventilator dependent. It was also expected that there would be a positive correlation with the level of depression and the percentage of life the child had been ventilator dependent. Rather, it was found that there was a negative correlation both with the level of posttraumatic stress and depression with the percentage of life that the child had been on the ventilator. Both with a medium effect size. As with the first hypothesis, this was opposite to what had been expected. Thus, the longer the child lived with the ventilator, the less significant pathology they exhibited. Studies have shown that if an individual feels control over their physical ailment then they are more likely to battle their ailment successfully (Crossland, 2000; Osowiecki & Compas, 1999). Therefore, this may suggest that the more recent the diagnosis or if an individual is nearing death, the individual would feel less control over their ailment. In regards to this study, it is possible that these children who have been ventilator dependent for an average of more than a year have reached a point that they feel control over or are accustomed to their ailment and are not exhibiting clinically significant symptomology.

Our third hypothesis proposed that there would be a positive correlation between child posttraumatic stress and depression and the primary caregivers level of stress. Both of these hypotheses were found to be true with a medium effect size; therefore, the data does suggest that the higher the level of stress the primary caregiver was experiencing, the higher the level of posttraumatic stress and depression the child exhibited. The same effect has been found in other studies. Freeman (2000) found when looking at the

psychological aspects of children who had undergone a heart transplant that the children's psychosocial functioning was related to parental stress, the higher the level of parental stress, the higher the level of the child's psychological pathology. Furthermore, it should be noted that the higher the parental stress level, the higher the level of anger the child may have been experiencing. This further supports Foy et al. (1996) and Pfefferbaum (1997) whose findings indicate children react to their parent's stress levels. Thus, similar to other pediatric populations, this data supports that ventilator dependent children's psychological adjustment is related to their parent's stress levels.

When further examining the data, it was found that in the scatterplots, when comparing the total depression score for the child with the primary caregivers stress the relationship appears to be influenced by the etiology of the ventilator dependency. Parents who have children who are ventilator dependent due to sleep apnea had higher levels of stress than the parents of children with an acute physical injury or neuromuscular disease. The children who had sleep apnea had been on the ventilator a shorter percentage of life than the other children had; therefore, the parents may be more stressed by this significant change in their child's functioning and may not have habituated to the ventilator dependency. Further, the children with sleep apnea exhibited higher levels of depression than the other groups. This may be because they are reacting to their parent's high levels of stress and because these children are not used to being on the ventilator and it makes them feel different from other children and limits their choice of activities. Also perhaps, because the child with sleep apnea is on the ventilator only at night these parents may get little sleep as they may constantly check on their child

because they are aware that their child's primary medical problem is a sleep disorder. This phenomenon begs further investigation in this population, as it is increasingly evident that as the parent's stress levels increase, the child has a more difficult time adjusting to their life psychologically. As in other studies, the data here reminds us that a child's adjustment is intricately related to the parent's adjustment.

Unfortunately, due to the lack of subjects who were ventilator dependent due to an acute physical injury, our final hypothesis, which proposed that for children with an acute physical injury there would be a negative correlation between the level of posttraumatic stress and depression and the level of breakage in the spine, was not able to be addressed. The two children who did exhibit an acute physical injury had the same point of breakage in the spine. However, it is noted that these two children were the only two children who were ventilator dependent for 24 hours per day and they were the two children who had been ventilator dependent for the largest percentage of their life. Furthermore, it should be noted that out of all the children they were the only children who answered the highest level that they were afraid of being disconnected from the ventilator. Interestingly, contrary to what had been expected, rather than acute injury, the researchers were surprised to find that the majority of the children in this study were ventilator dependent due to sleep apnea.

The discovery that sleep apnea was a primary factor for ventilator dependency led to an interesting finding in that there appears to be a relationship between the child's BMI and his or her level of anxiety. The higher the child's BMI level the higher his or her anxiety level. It was also found that children with acute physical injuries exhibited less

feelings of ineffectiveness, while children with sleep apnea were found to have higher levels of ineffectiveness. This may have been because the children who had suffered an acute physical injury in this study had been ventilator dependent for a higher percentage of their life and they did not see themselves as different. Those with sleep apnea have a more insidious onset to their physical problems and there may be a relationship between the ineffectiveness and the fact that each of the children in this group were significantly obese. They may compare themselves to other children around them and feel more poignantly that they are now limited. Another psychological factor is that they are on a ventilator without a trauma to explain their new physical dependency. There was no external cause to blame for their need of a ventilator. Also, they have been on the ventilator for a shorter percentage of life and they may more recently have limited their activities. It is also possible that the research data was picking up peer distress and problems related to physical size rather than distress related to a traumatic event.

Since a significant portion of the subjects are obese, it is important to address the psychological profiles of obese children. Seven out of the nine subjects were above the 95^{th} percentile on their BMI scores which put those children in the upper range of obesity. Because the sample was so small and skewed to the sleep apnea group, it is plausible that the data is picking up more concerns related to obesity in children rather than children on ventilators per se. However, research which addresses issues of obesity in children, reports that children who are obese often do not show up as different from a nonobese population in regards to psychological functioning (Friedman & Browness, 1995). It is suggested by these researchers, that this may be because studies have looked

at global and total scores on assessments in areas such as anxiety and depression. It is also suggested that obese children do exhibit psychological issues on the subscales of many of the assessments and it is further emphasized that testing with obese populations should be more unique and specific to the population (Friedman & Brownell, 1995). Pierce and Wardle (1997) report that self-esteem may be the most significant psychological issue related to childhood obesity. As this study intended to address trauma rather than obesity, issues surrounding self-esteem were not adequately assessed in the current data.

In a study in progress by Mitchell et al. (2001) which is examining a group of obese children in a clinical program, boys have not been found to exhibit significant depression issues on the CDI. However, these boys do express clinically significant levels on the Piers Harris Inventory which evaluates self-esteem. The girls in the study however, are presenting significant issues on the CDI. Given the fact that there were twice as many boys then there were girls in the present study, it raises the possibility that the levels of depression were not showing up on the CDI due to gender related issues. Friedman and Brownell (1995) stated that in comparing obese to non-obese individuals there was little to no difference in psychological aspects such as depression and anxiety. However, they caution this as a naïve assumption as this was not their clinical experience. They emphasize the influence of methodology of these particular studies. Specifically, are we really measuring what we intended to measure in these unique medical populations.

The present study must also address this same methodological question. The study was designed to examine the issues of trauma and perhaps did not pick up the pathology of these children's experience. Rather, the results of this study, by nature of the demographics of the subjects and the etiology of ventilator dependency, may have more accurately identified psychological issues of obesity rather than acute trauma. Further, it should be noted that even in regards to assessment of trauma, the standardized tests used for this study were not specific to these children's medical condition. While some ventilator dependent questions were devised, the research may not have fully addressed the potential psychopathology of the children's true experience in relation to ventilator dependency.

Ventilator dependent questions which were devised addressed the child's sleep pattern, dreams, fears, and past emergencies. Most of the children's answers were vague with no related concerns. Many of the children stated that they did not remember their dreams, they slept fine, and if they were scared of anything it was usually in relation to something such as spiders. It appeared that there was no significant pattern or relation to the experience of being on a ventilator. One exception was the question of how scared the child was of being disconnected from the ventilator. The data showed that the more hours per day the child was on the ventilator and the higher percentage of life that the child was on the ventilator, the more fearful they were of being disconnected from the ventilator. This may be because the child has an understanding of what the ventilator is to them. To them, it represents their life, because they know that if they are disconnected, they will not live. As well, the child over time gains a better understanding

of how much can go wrong with a ventilator and how much it is depended upon. The fear of the child being disconnected from the ventilator and the TSCC-A anxiety scale negatively correlated with a medium-large effect. This result may be due to the small number of subjects or the possibility that there are different types of anxieties and the TSCC-A reflects a different anxiety then is manifested by ventilator dependent children in relation to their dependency.

Further, the longer you are ventilator dependent, the more ventilator dependent children you will get to know through medical appointments and interactions. Several of the children have had other friends in the ventilator dependency program that were on a ventilator and died due to complications with their ventilator. This makes the understanding of how much they depend on their ventilator for life very evident. Also, in regards to the higher amount of fear in the child who is dependent more hours of the day, the child who is on the ventilator for 24 hours per day realizes that there is no way that they would be able to survive without the ventilator. However, the child that is on the ventilator for less then 24 hours a day may realize that they can live without the ventilator at times; therefore, they may feel that there would be a chance that if they were disconnected they would be able to still live.

This raises the possibility that the standardized tests utilized in this study were unable to pick up the specific issues that are unique to ventilator dependency. It appears that these children are fearful and do have anxiety about specific issues that are pertinent to their specific situation. These children are experiencing pathology that is specific to their illness and this does require further investigation.

When examining the standardized T scores for each individual child, there was only one child who exhibited clinically significant scores on the CDI total scale, TSCC-A anxiety scale, TSCC-A anger scale, or TSCC-A posttraumatic stress scale. This child had sleep apnea and was grossly obese. From looking at all of the other standardized scores, it appeared that these children were comparable to the average child found in the normative data. It should be noted however that there were a number of scores that were below the T score of 50. This may be interpreted to mean that in these specific areas, the research group may be doing psychologically better than the normal population. However, it may also be that these children are overcompensating for what they may feel are personal weaknesses. This phenomenon has been seen in parents who had children who received heart transplants as well (Freeman, 2000). Some studies report that when individuals have faced or are facing major medical situations, individuals may tend to be defensive or overcompensate for their loss. Children who suffer from a physical ailment then may be defensive and answer in a way that they feel will make them look like an average child their age or give answers that they feel would be the best answer according to the examiner.

Limitations

The most significant concern in regards to the limitations of the study was the extremely small sample size. Unfortunately with the small sample size there was little power for the analyses. This makes it difficult to generalize the results to other ventilator dependent populations.

Another limitation in the current study is that outliers may be driving the analysis. Although there were no outliers that deviated more than three standard deviations away from the mean, there was one subject whom differed greatly from the other children on the measures. When observing appendix I, it is clear that one child with sleep apnea was pulling up the regression.

As well, there may have been a problem of accurate self-reporting since there was not much time given to build rapport with the children before very personal questions were asked. Because of the handicaps of the patients, the children were given the written protocols orally which discussed issues such as had the child ever thought about killing herself, did she ever feel mean, did she do what she was told, did she feel like she had plenty of friends, did she feel afraid, did she feel lonely, etc. These questions were asked of the children within 15 minutes of meeting them and this may have hindered the children from answering honestly. They may have attempted to make themselves sound more "normal." Furthermore, each questionnaire for the child was standardized as a self-report measure. Unfortunately, due to the nature of the disabilities the subjects experienced, the children were unable to read and mark the answers on their own. Therefore, the questionnaires were read to the children. This may have suppressed some of their answers and caused them to respond in a different way than they would have, had they been able to read and fill out the questionnaires on their own. Social desirability may have been a factor as well, with the child attempting to answer in a way that would be more accepted in their eyes.

It may also be a problem that the data did not have an equal or adequate representation of any one subgroup of ventilator dependent children. The subjects included six Hispanics, two Caucasians, and one Asian. There were a total of six males and three females. Also, in terms of etiology of ventilator dependency there were five due to sleep apnea, two due to acute physical injury, and two due to neuromuscular disease. Therefore, it was not possible to discriminate between any of the subgroups. Another limitation, which was related to the small group size, was that the data did not provide variability within the acute physical injury group. Therefore, it was impossible to look at the differences in spinal cord injury and posttraumatic stress.

Further, it appears that the questionnaires that the researcher chose to use were not specific enough to the child's medical condition and the child's pathology did not show up on the scales. The questionnaires appeared to not be picking up the psychological distress that these children may be experiencing as evidenced by the clinicians experience with these children. Rather than an acute trauma, these children appear to be suffering from a disease known as obesity. Obesity has a gradual onset and causes debilitation over a long period of time. This study was not intended to address obesity; therefore, the measures used were geared more toward a population that had experienced an acute or body trauma rather than issues of an indicidious process such as obesity. These children may in actuality not be traumatized per se. Also, as discussed earlier, obese males rate themselves higher on self-esteem issues rather than depression, which the current study did not evaluate. Thus, the questionnaires which were directly assessing posttraumatic stress and depression may not have been the best measures as the research population was

mainly comprised of children who had not been in an acute traumatic experience and the child may not have viewed the ventilator as being traumatic, rather they may be slowly habituating to their disease.

Future direction

Though this was a study with a small sample, there were several results that appeared to be significant and worth exploring further. First of all, a larger sample would help confirm the accuracy of the results and give more power to the analyses. As well, it would be suggested that further studies note the study population and in addition, add a measure which specifically addresses the ventilator experience. The CDI and TSCC-A look at global aspects of depression and issues which relate to posttraumatic stress and may relate to more acute trauma; however, the measures do not ask specific questions about some of the experiences a child who is ventilator dependent would go through. Questions which were more specific to this population such as is the child afraid of getting disconnected from the ventilator and are they afraid of dying from an emergency with the ventilator may reveal more of the concerns of this particular population. Also, it may be that since the research appeared to include a significant amount of obese children, issues specific to obesity such as self-esteem should have been raised and future protocols should include these factors.

More specific and population unique questions may be raised to view whether these children view their experience as traumatic? It appears that they may exhibit resiliency against forming negative pathology. Though, it may be possible that the researchers only sampled the children who had formed resiliency because of the limited

acute trauma in the sample. Further exploration that would be of value to understand is in the correlation between parental stress and child distress and/or child anger. That is, whether or not the children are exhibiting their own pathology or if they are reacting to their parent's high levels of stress. On the other side of the issue, it would be important to understand if the child is reacting to the parental stress or if the child and his or her experience is causing the exacerbation of the parental stress.

Future questions may include whether these children's verbal ability's were always low or if they became progressively lower as their prognosis neared the need for ventilator dependence and after. It may also address the issue of ethnicity and an individual's first language. Were the children scoring low on the PPVT-III because of their ethnicity and the possibility of English not being the child's first language? If the participants were using English as their second language, it may be that their English verbal skills were minimal. Though all of the participants were able to communicate in English, there were three times as many Hispanic subjects than there were Caucasian subjects and six times more Hispanic subjects than there were Asian subjects.

It is important to understand the demographics of ventilator dependent children in the United States. This small study emphasizes the need to discover if the research data was representative of ethnicity and the etiology for ventilator dependence. In the US, obesity is quite high among the Hispanic youth. It is important to know whether obesity is a significant issue across the larger ventilator dependent population as well as to understand whether obesity is a significant contributor to the growing population of

ventilator dependent children. Obesity appeared to be a key issue in the research and these issues must be addressed in order to serve this population.

It may be necessary to develop a specific measure to understand these children's experience. The measure may need to take into account the weight of the child and the reason that they are ventilator dependent. It may be helpful to understand if these children are comparing themselves to other children or if they are experiencing actual signs of depression.

It is clear that these children are having problems such as the fear of being disconnected from the ventilator, issues surrounding obesity, and slightly higher levels of anxiety; however, it is also clear that the research data does not address all the unique concerns of these children. The findings of the research population included strong indicators that obesity and parental stress levels are the issues that need to be further explored in the population of children who are ventilator dependent. As well, it needs to be noted that though the current research was assuming that they would be looking at acute trauma, the population was largely representative of a gradual onset of circumstance. Obesity in America is on the rise. It is clear that children who are ventilator dependent are under some type of distress and though the sample population did not see much acute trauma, no matter what the reason for ventilator dependency, these children are experiencing some negative psychopathology. These children have a unique experience that is greatly understudied. The dearth of research in the area is inexcusable. It is imperative that future research explore and try to truly understand these children's experiences.

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Appendix A

Telephone Script

"Hello, my name is Tanya Burley and I am a psychological trainee from Loma Linda University and I am working on a study with Dr. Van Stralen and Tammy Young from the Home Ventilation Program. We are working on a study that involves ventilator dependent children. We are looking at some of the emotions that children who are ventilator dependent may experience. If you agree to this study, you and your child will participate by fill out a couple of questionnaires which look at feelings and behaviors. This would be done during a regularly scheduled appointment at the vent clinic at the FMO. I would like to ask your permission for you and your child to participate in this study. Be assured that your willingness to participate is completely voluntary and will not affect your regular medical follow up in any way. Would you be willing to look over the consent form and participate in this study?"

If individual says yes, I will ask to make an appointment to meet with them at the clinic and say "I will have you sign a consent form which will give you more information about the study when you arrive for the appointment and we will begin the assessment that day if you decide to participate. Thank you for your time and I will be happy to meet you at the clinic."

If the individual says no, I will say, "thank you for your time and have a nice day."

Appendix B

Cover Letter for Informed Consent and Informed Consent

LOMA LINDA UNIVERSITY

Dear Parent,

Thank you for considering being a part of a very important research project. As you were told on the phone, I am working on a study with Dr. van Stralen and Tammy Young here at the Home Mechanical Ventilation Clinic. I will be supervised by Kiti Freier, Ph.D., a pediatiric psychologist here at Loma Linda. The following pages explain the study in detail and let you know what your and your child's rights are.

As you know you will be asked to fill out some questionnaires and I will be reading and marking your child's response to three questionnaires. It is our hope to understand you and your child's experience with ventilators a little more. It is also our hope that ventilator dependent individuals will benefit in the future from the findings of this study. All information will be held in strict confidence.

Thank you for your cooperation with this study. Referrals will be provided at the time of termination in the event that you or your child feel that you may need to talk to someone further about your feelings.

Sincerely,

Tanya Burley
Psychology Trainee

LOMA LINDA UNIVERSITY

aduate School
partment of Psychology

11130 Anderson Street
Loma Linda, California 92350
(909) 558-8577
FAX: (909) 558-0171

Parent Informed Consent
Psychological Aspects of Ventilator Dependent Children

You and your child are invited to participate in a research study since you are part of the Home Ventilation Program here at Loma Linda University Medical Center. Before you give your consent, please read through this entire document.

Purpose of the Research

The purpose of this research study is to learn more about emotions in children who are dependent on a ventilator. As we learn more about how ventilator-dependent children feel about themselves and their lives, we may have the opportunity to develop appropriate preventions or interventions to help these children with their emotions.

Procedure

If you agree for your child and yourself to participate in this study, you will be asked to fill out two questionnaires and your child will have two questionnaires read to him or her during one of your routine visits to the Home Mechanical Ventilation Program at the Faculty Medical Offices in Loma Linda, California. The questionnaires have questions that ask your child about different feelings they may have including fear, sadness, and other emotions that may be a part of your child's experience with his or her ventilator. You will be asked to fill out a questionnaire that asks questions about your child and a questionnaire that asks you questions about some of your concerns, frustrations, and worries. The entire process will take about 45 minutes. Your child's BMI (Body Mass Index) score will also used from his medical record.

_____ Initials
_____ Date

Risks/Discomforts

During or after your child fills out the questionnaire, he or she may have uncomfortable feelings about the experience of being ventilator dependent. The questions that your child will be asked will include statements that make them think about their fears and how they feel about themselves. You or your child will have the right to stop at any time during the process. The committee at Loma Linda University that reviews human studies (Institutional Review Board) has determined that participating in this study exposes your child to minimal risk of emotional distress.

Benefits of the Research

While it is unlikely that you or your child will experience any personal benefit for participating in this study, there is a possibility that your child may have the opportunity to see if he or she would benefit from some personal or group counseling. It is hoped that individuals who are ventilator dependent will benefit in the future from the findings of this study.

Participants Rights

Participation in this study is completely voluntary. You and your child are free to refuse to participate in this study and may stop answering the questions at any time. Your decision to participate or not will not affect your childs present or future care at the Home Ventilator Program.

Confidentiality

Any document resulting from this study will not disclose the identity of participants, unless you give your permission, no one else but the study investigators will be given any information about individuals responses.

Additional Costs/Reimbursements

There will be no costs to you for participating in this study. You will not be compensated in any way.

_____ Initials
_____ Date

Psychological Aspects of Ventilator Dependent Children

Impartial Third Party Contact

If you wish to contact an impartial third party not associated with this study regarding any complaint or concern you may have about the study, you may contact the patient representatives office at Loma Linda University Medical Center, Loma Linda, CA 92354, phone (909) 558-4647 for information and assistance.

Informed Consent

I have read the contents of the consent form and have listened to the verbal explanation given by the investigator. My questions concerning this study have been answered to my satisfaction. I hereby give voluntary consent for my child to participate in this study. Signing this consent document does not waive my rights nor does it release the investigators or institution from their responsibilities. I may call Tanya Burley, psychology trainee at (909) 558-1165 or Kiti Freier, PhD, her supervisor at (909) 558-8577, if I have additional questions or concerns.

I have kept a copy of this consent form.

_____ _____

Signature of Primary Caregiver Date

_____ _____

Witness Date

_____ Initials

_____ Date

Appendix C

Assent Form

LOMA LINDA UNIVERSITY

aduate School
partment of Psychology

11130 Anderson Street
Loma Linda, California 92350
(909) 558-8577
FAX: (909) 558-0171

Child Assent Form
Psychological Aspects of Ventilator Dependent Children

You have been asked to be part of a project with other children that are on ventilators. The project is to see if children on ventilators experience fear and sadness. A graduate student, Tanya Burley, along with Dr. Van Stralen and Tammy Young will be working on this project.

If you decide to be a part of this project, Tanya will talk to you at the Home Mechanical Ventilation Program on one of your regular visits. She will read questions to you and have you answer them. The questions are about how you feel some times, like if you are scared or sad. The project will take about 45 minutes.

No one except the people doing the project will know what you say.

Answering these questions may not help you right now, but it may someday help other kids like you.

You don't have to be in the project if you don't want to. If you start the project, but change your mind or get upset and want to stop, that is O.K., you can stop anytime you want. If you do stop, no one will be unhappy with you.

Thank you for your cooperation and if you have any questions about anything, please ask Tanya now.

I give my permission to be a part of this study. I have been given a copy of this form to keep.

Name_____ Date_____

_____ _____

Signature of data collector Date

Appendix D

Parental Questionnaire

Please answer the following questions regarding your ventilator dependent child.

Name of respondent and relationship to child_____

Name of child _____

Age of child_____

Date of Birth of child_____

Gender of child_____

Ethnicity of child_____

What is your childs medical diagnosis? _____

If your child is dependent upon a ventilator due to spinal cord injury, at what location along the spine is your child's injury?_____

If your child has been diagnosed with a neuromuscular disease, is there anyone else in the family with this type of disease? Yes No

If yes, who (in relation to your child)?_____

If deceased, at what age did they die?_____

Number of caregivers (helping with the child for at least 2 hours a day) in the home_____

Is your child able to communicate verbally? Yes No

Is there a home-health nurse that comes in to help with daily living? Yes No

If yes, for how many hours a day?_____

How many hours a day is your child ventilator dependent?_____hours

How long has your child been ventilator dependent? _____years

What type of ventilator does your child use?_____

Is your child's ventilator invasive or noninvasive? Invasive Noninvasive

Has your child ever been weaned off of the ventilator? Yes No

If yes, how many times and when?_____

Has your child ever been accidentally disconnected from the ventilator device? Yes No

If so, how many times?_____

Has there ever been a time that the ventilators alarm was not heard for responded to right away? Yes No

If yes, how many times?_____

Is your child able to move any of his/her arms or legs? Yes No

If yes, which arm(s) or leg(s)?_____

Is your child in a wheelchair? Yes No

If yes, how many hours a day?_____

Is or has your child ever received any psychological counseling? Yes No

If yes, for how long?_____

Thank you for your cooperation in this study.

Appendix E

Child Questionnaire
(To be read to child)

1. What are some of your favorite things to do?

2. Are your parents married?

3. Who do you live with?

4. Who do you trust the most with taking care of you?

    How often are they the one to take care of you?

5. Have you ever moved to a new town?

    If yes, when and how often?

6. What best describes your sleep?
    Hard to fall asleep
    Wake up several times
    Wake up early in the morning
    No problems sleeping

7. Are you ever afraid to go to sleep at night?

    If so, Why?

8. Do you have dreams?

    If so, what do you dream about?

9. What scares you?

10. How does it make you feel when you think you may have to go back to the hospital?

11. Do you trust your ventilator?

12. Do you have any friends or relatives that are ventilator dependent?

    If so, who?

13. Have any of these people died?

If so, who and what happened to them?

14. Has anyone close to you died in the past year?

If so, who and what happened?

15. On a scale of 1 to 5 with five being the most scared, how scared are you of being disconnected from your ventilator?

16. Have you ever had an emergency with your ventilator?

If so, what happened?

17. Have paramedics ever come to help you?

18. Do you have friends?

Are your classmates mean to you?

19. Tell me about school.

Appendix F

Follow Up Letter

LOMA LINDA UNIVERSITY

iduate School
>artment of Psychology

11130 Anderson Street
Loma Linda, California 92350
(909) 558-8577
FAX: (909) 558-0171

Dear Parent:

Thank you for allowing your child to participate in this study. Your child was given a short test that showed whether or not he or she would be able to understand the questions that I gave them for the purpose of the study. Next, they were asked to answer questions about their experience with the ventilator. Lastly, they were asked to answer questions that were pertaining to any sadness, anxiety, or fear that they are currently experiencing.

It has been found in numerous studies that individuals who have gone through invasive medical procedures, experienced a sudden injury, are dependent on others for help, and who have been hospitalized go through a lot of stress. These experiences, at times, cause more than normal amounts of anxiety and depression.

It was the purpose of this study to measure the level of stress, fear, anxiety and depression children who are ventilator dependent show so that we will have a better sense of the problems children face and how to intervene more appropriately and adequately.

Please feel free to call me with any questions that you may have regarding the study. Unfortunately, the study will not be complete until approximately the summer of 2001. My number is (909) 558-1165. My supervisor, Dr. Kiti Freier, Associate professor of psychology and Pediatrics at Loma Linda University may be reached at (909) 558-8577.

If you or your child feels any distress over the questions that you were asked during this process, or if you feel that you or your child would benefit from being able to talk to a professional about any problems you or your child may have such as a lot of sadness, fear, worries, or stress, please feel free to call SAC Norton Behavioral Health Clinic at (909) 382-7135 or Psychological Services Clinic at (909)558-8576.

Thank you again for your participation. It was greatly appreciated.
Sincerely,

Tanya R Burley

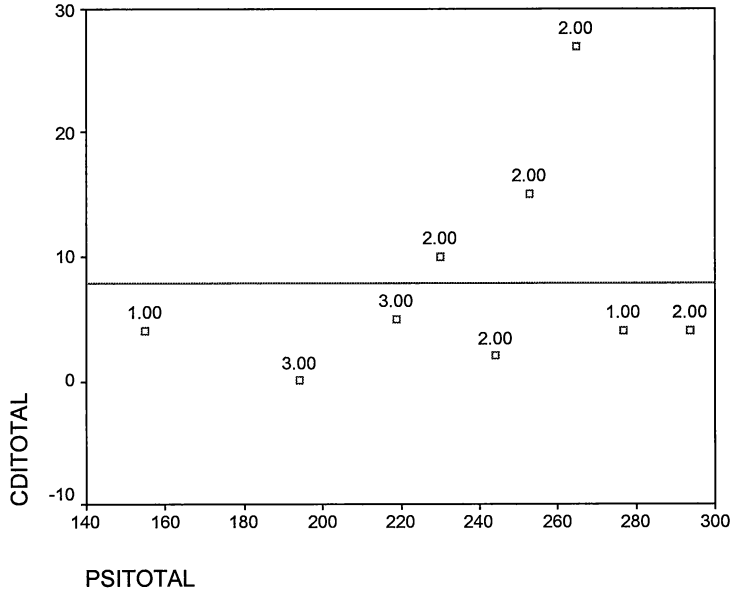
Tanya R. Burley
Doctoral Student of Psychology

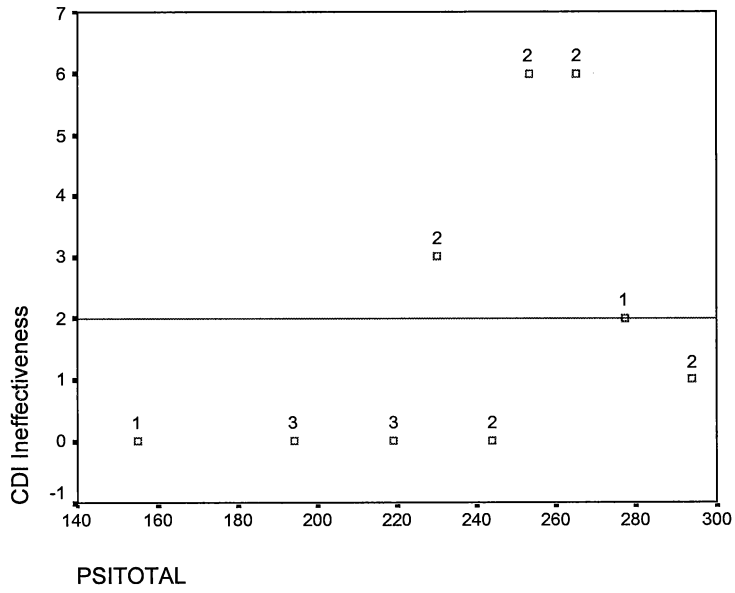
LOMA LINDA UNIVERSITY
INSTITUTIONAL REVIEW BOARD
APPROVED 2/28/01 USED AFTER 2/28/02
#40309

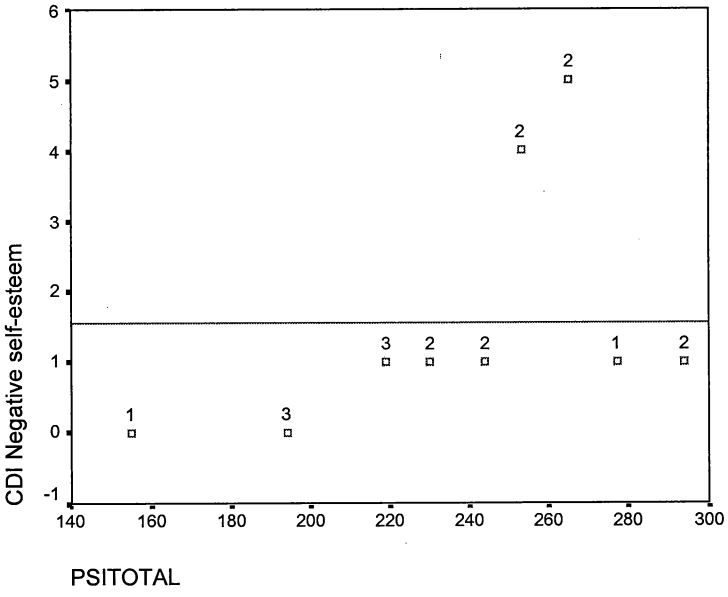
Appendix G

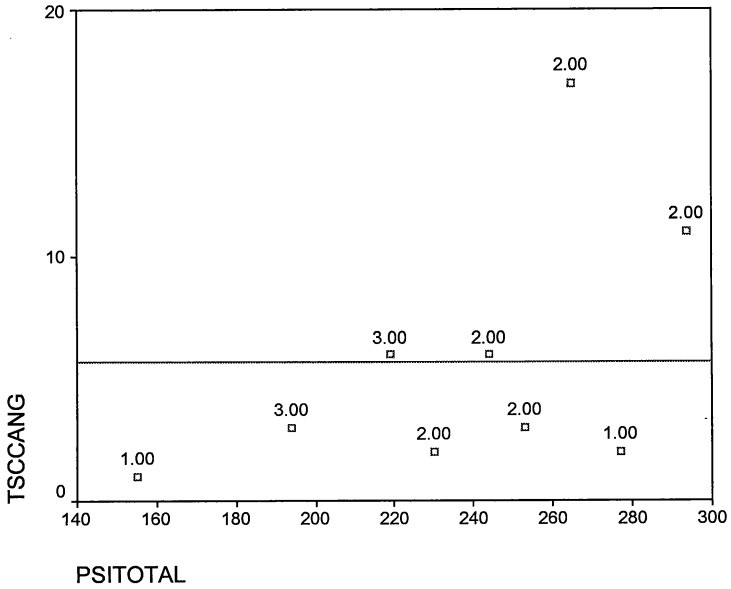
Scatterplots with PSI scores

1= Neuromuscular disease
2= Sleep apnea
3= Acute physical injury





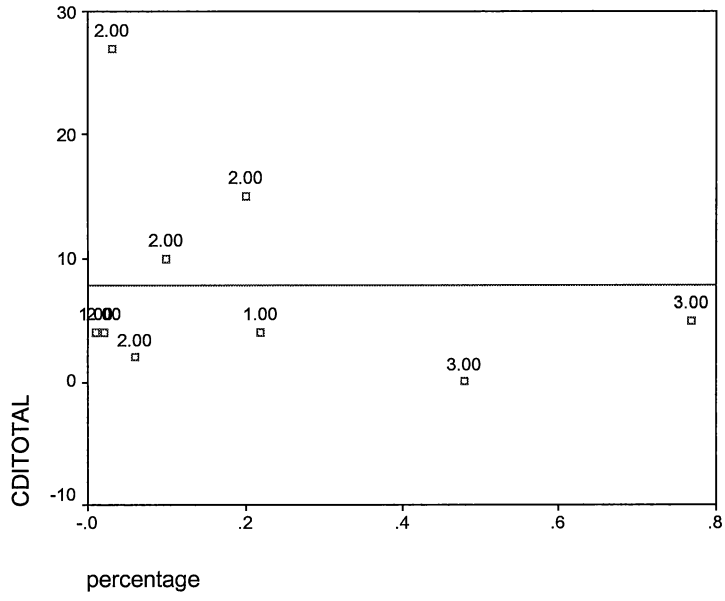

CDI Negative self-esteem
6
5
4
3
2
1
0
-1
140
160
180
200
220
240
260
280
300
PSITOTAL
1
3
3
2
2
2
1
2

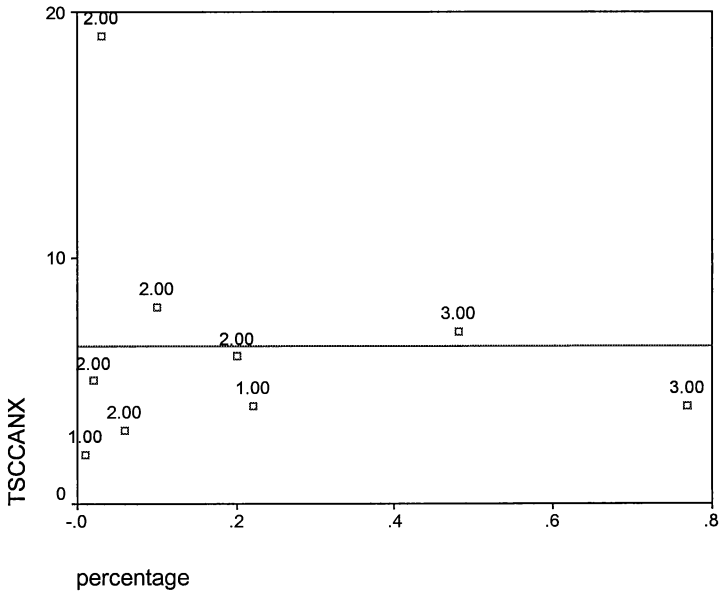

TSCCANG
20
10
0
140
160
180
200
220
240
260
280
300
PSITOTAL
1.00
3.00
3.00
2.00
2.00
2.00
2.00
1.00
2.00

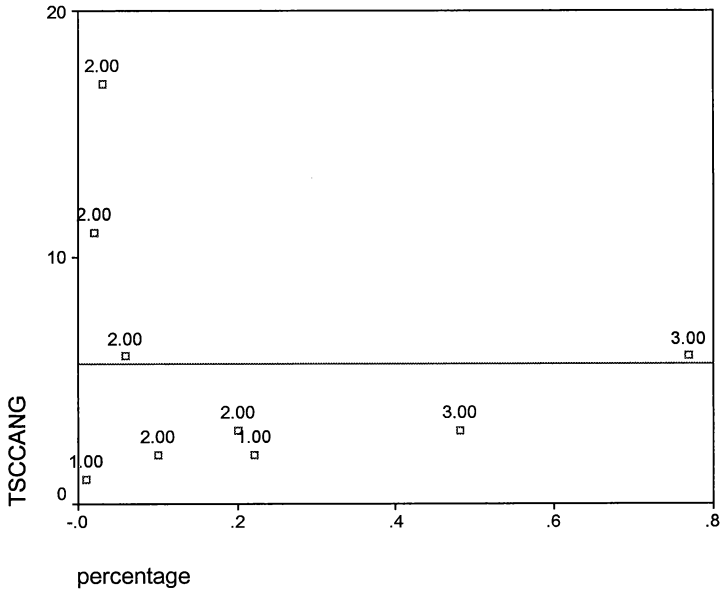
Appendix H

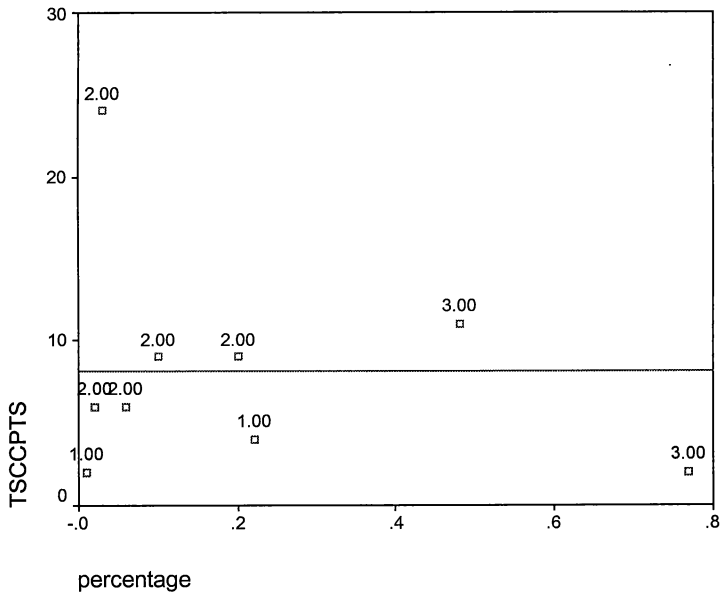
Scatterplots of percentage of life on ventilator

1= Neuromuscular disease
2= Sleep apnea
3= Acute physical injury




20
10
0
TSCCANX
2.00
2.00
3.00
2.00
2.00
1.00
3.00
2.00
1.00
-.0
.2
.4
.6
.8
percentage

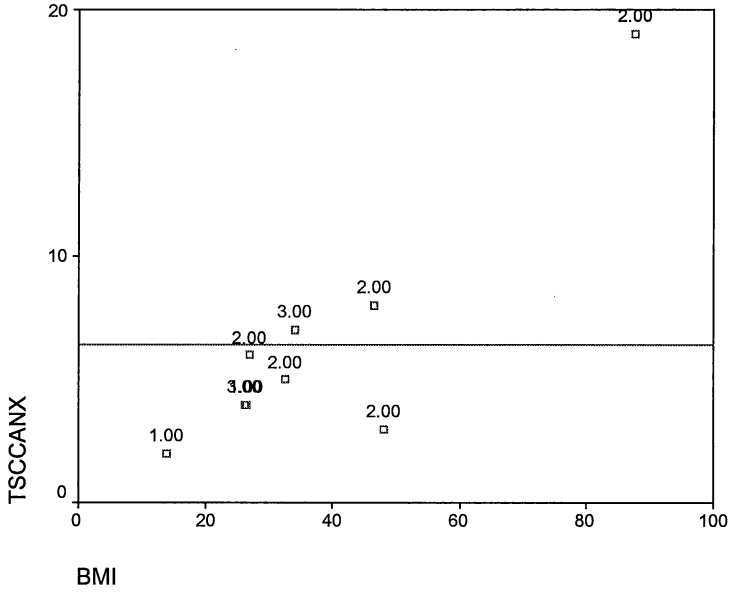

20
10
0
TSCCANG
2.00
2.00
2.00
3.00
2.00
3.00
2.00
1.00
1.00
-.0
.2
.4
.6
.8
percentage

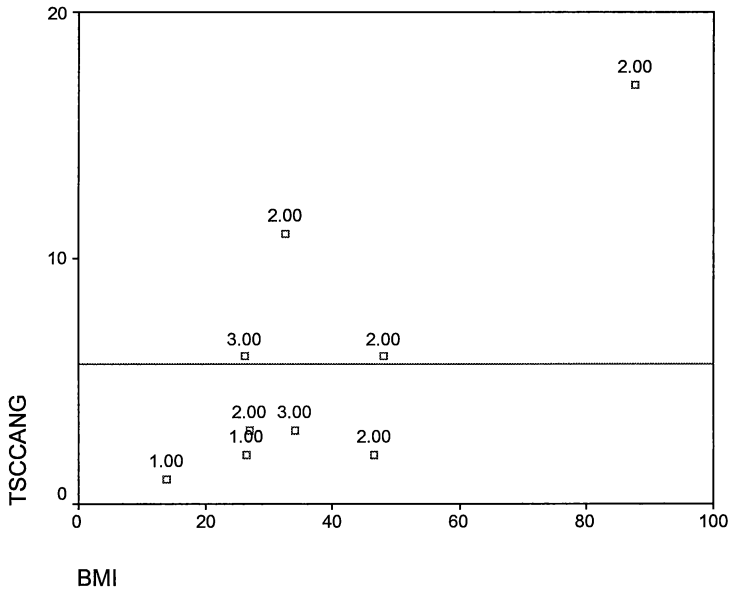

30
20
10
0
TSCCPTS
2.00
2.00
2.00
2.00
2.00
1.00
1.00
3.00
3.00
-.0
.2
.4
.6
.8
percentage

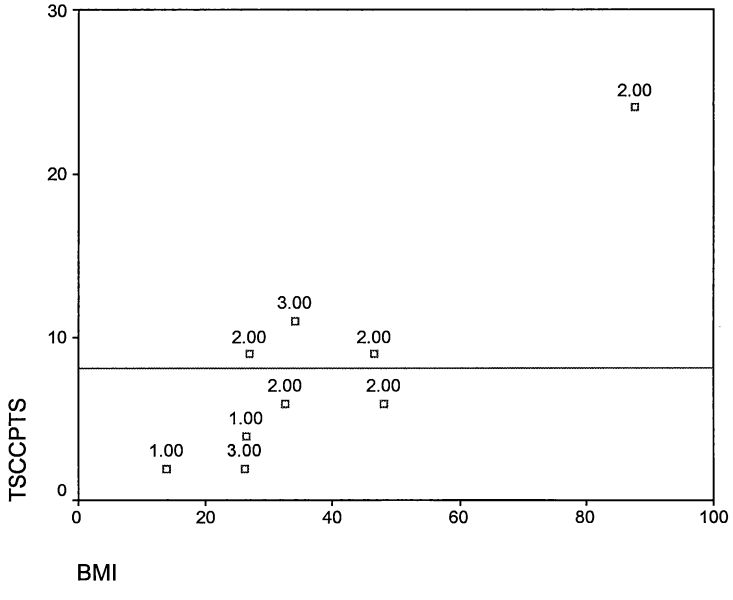
Appendix I

Scatterplots of BMI scores

1= Neuromuscular disease
2= Sleep apnea
3= Acute physical injury




TSCCANG
BMI
20
10
0
0
20
40
60
80
100
2.00
2.00
3.00
2.00
2.00
3.00
1.00
2.00
1.00


TSCCPTS
BMI
30
20
10
0
0
20
40
60
80
100
2.00
3.00
2.00
2.00
2.00
2.00
1.00
1.00
3.00