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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

FEASIBILITY STUDY AMONG MILITARY PERSONNEL WITH
TRAUMATIC AMPUTATION DURING MILITARY COMBAT OR TRAINING

By

Michele (Shelly) R. Burdette-Taylor RN-BC, MSN, CWCN, CFCN

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
UNIVERSITY OF SAN DIEGO

In fulfillment of the
Requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

December 21, 2010

Dissertation Committee

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Abstract

Military operations have resulted in a significant number of mangled extremities leading to traumatic amputations. Extremity injuries predominate, representing 50% to 70% of all injuries treated. The majority of injuries sustained in Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) are combined penetrating, burn and blast injuries, traumatic amputation, and infections from the multi-drug resistant organism, *Acinetobacter* (Melcer, 2010).

The purpose of this study was to measure the quality of well-being and impact of events in a group of adults who served in the U.S. armed forces *and* sustained the loss of one or more limbs during any combat or military training activity. The specific aims of this study are:

- 1) To describe the level of well-being (e.g., degree of mobility, physical/social activity, pain, anxiety, depression, anorexia, fatigue) and level of Post Traumatic Stress Disorder (PTSD) symptoms (e.g., degree of intrusive thoughts, intentional avoidance, hyperarousal).
- 2) To describe relevant personal, environmental, and disability factors in adult military personnel, specifically personal factors (e.g., age, gender, ethnicity); environmental factors (e.g., current living situation); and disability factors (e.g., number of amputations, location of amputations).
- 3) To examine the relationship between levels of well-being, PTSD symptoms, and relevant personal, environmental, and disability factors.

An analysis of a chronological account of events and a description of all of the approaches attempted was compiled. The researcher was well qualified to conduct the

study and did everything possible to encourage participation, but was unable to complete the research as designed due to insufficient enrollment. The possible explanations for the behaviors of potential subjects were numerous and include political, chain of command, fear of retribution, feelings of being overwhelmed, apathy, signs and symptoms of phantom limb pain, and depression.

Although the aims of the study were not realized as designed, much can be learned about this population because of these efforts. What follows is a description of the extraordinary efforts made to recruit subjects. Next are the uses of Yin's (2009) framework to explore the related rival explanations that contributed to the feasibility of study completion. The conclusion discusses the implication for successful future research.

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DEDICATION

This dissertation is dedicated in honor of my husband, Thomas G. Taylor, and our four awesome children, Ryan, Erica, Dane, and Bridget, as well as my mother N. Jean Donnan, who collectively have supported my efforts in anything chosen to be done.

In memory of one of my best friends in the whole wide world; my mother-in-law, Betty Jayne Taylor, born December 21, 1922, and who unfortunately died during the dissertation phase of this study.

ACKNOWLEDGEMENTS

Family are most personally affected by a project of this magnitude. Therefore, thanks to my mom Norma Jean who edits regularly, my husband Tom who continues to endure my shenanigans, my four children – Ryan, Erica, Dane, and Bridget – who are always in wonder, and our animals – Amber, Reilly, Socks, and Dill.

Thanks to my professors and committee members, especially Dr. Jane Georges – Chair; YOU are PHENOMENAL, Dr. Cynthia D. Connelly – amazing, and Dr. Dee Cannon who convinced me one day at Denny’s that now, I am an expert in PTSD (P.S. I am a foot care/wound care nurse). Thanks, Dee, for your faith in me and all of the support for dissertation completion.

I must acknowledge and give heartfelt thanks to:

Dr. Patricia Roth for rallying so many of us in 2004-2005 and encouraging us to believe we could succeed. Dr. Ann Mayo for putting the PhD seed in my head in 1992.

Dr. Donna Agan for her continued support in so many ways since the first day I sat in her statistics class, as a professor and now friend. Dr. Mary Jo Clark for her contributions to a chapter in my foot care textbook in her writing class.

Dr. Mary-Rose Mueller for her gift of qualitative research and suggestion to read and critique Dr. Gay Becker’s book on *Disrupted lives: How people make meaning in a chaotic world*. Who would have known it would apply directly to my attempt to understand the chaos affecting our wounded warriors?

It takes an Army Village to work on an Army Project, especially with a vulnerable population that has had their world turned upside down. Thanks to my commander, LTC Margaret Ramsdell, and MAJ James Greenlee who supported, listened

and guided me; my combat medic co-instructors, MSG Ali Parviz, SFC Rob Fleishman, SGT Cadiz, SGT Nelson, SGT Jackson, and the *other* nurse, el CPT Joy Sanders. They heard the stories every battle assembly weekend, recruited actively, and walked the 5Ks in support of wounded warrior projects and mental health issues.

As a nurse blessed with many friends in the military and civilian sector, I can only list the affiliations that have provided guidance – Palomar Pomerado Health, Silverado Senior Living, Penasquitos Lutheran Church, Armed Forces YMCA, Naval Medical Center - San Diego, Walter Reed National Military Medical Center, Veterans Hospital of San Diego, Heroes to HomeTown, and 9th BN, 4th BDE, 100th DIV U.S. Army Reserves.

My strength comes from children, so thank you: (new baby on the way in NC) and Zia James, Camry, Alex, Ian, Sami, Kayleigh, Anthony, Steven, Breanne, Justin, Artemy, Chiko, Clint, Bridget (dill), Kyla, Matt, Lei Lei, Cody, Dane, Lauren, Krystal, Erica, Ashley, Ryan, and David. You will always be the JOY in my life.

My final acknowledgements are my FAVS – Cece, Cindy, Debi, Dee, Delphine, Denny, Donna, Elizabeth, Erin, Greta, Jane, Karen, Kathy, Mary, Stoia Ann, Teresa, Tina, Susie, and Bob, Don, Glenn, and Pastor Sean. Where would the world be without soul mates? It goes to show you that if you have a strong team – YOU really can do ANY thing. This whole project and process was about the soldiers, and continues to be, as I accept an active duty position in U.S. Army as a case manager for wounded warriors at a Community-Based Warrior Transition Unit.

Hearty hugs to all. Pray for the wounded warriors and their families; they have given the ultimate – time, separation from family, courage, limb, and life.

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Chapter 1

Introduction

Statement of the Problem

Military operations in Afghanistan (Operation Enduring Freedom) and Iraq (Operation Iraqi Freedom) have resulted in a significant number of soft tissue, vascular, and orthopedic injuries leading to traumatic amputations. Extremity injuries predominate, representing 50% to 70% of all injuries treated during Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF; Melcer, Walker, Galarneau, Belnap, & Konoske, 2010). Exsanguinations from extremity wounds are the leading cause of preventable death on the modern battlefield. The battlefield has a reputation of being unclean, noisy, and lacking valuable resources. High-kinetic energy injuries, such as improvised explosive devices (IEDs), often cause soft-tissue, vascular, neural, and orthopedic destruction that leads to amputation. Local and systemic infections from resistant organisms lead to further damage and greater loss of limb, if not life itself.

Traumatic amputation due to combat casualty presents unique medical, surgical, and rehabilitation challenges. The majority of injuries sustained in OEF/OIF are combined penetrating, blunt trauma, burn and blast injuries, traumatic amputation, and multi-drug resistant *Acinetobacter* infections (Melcer et al., 2010). The Department of

Defense (DOD; 2009) and CRS Report to Congress (Fischer, 2009) confirmed that 31,934 soldiers in OEF and 8,040 in OIF have been wounded in action; 1,286 are those with amputations, of which 35% involved upper extremity loss. Of the 1,286 amputees, 935 suffered major limb loss, often meaning more than one extremity (Department of Defense, 2009; Fischer, 2009). As of March 2009 (Fischer), 39,365 soldiers have been diagnosed and are being treated for post-traumatic stress disorder (PTSD). Twenty seven percent of the military personnel deployed are now enrolled in a VA specialized care program for PTSD (Fischer; Meagher, 2007). This study proposed to measure the quality of well-being and impact of events with military personnel who returned from combat or sustained one or more limbs lost due to military related traumatic injury. Quality of well-being is closely related to the quality of life and is directly affected by the severity of PTSD, especially after traumatic limb loss (Copuroglu, Ozcan, Yilmaz, Gorgulu, Abay & Yalniz, 2010). Many studies have been published investigating issues with recent combat amputees (Covey et al., 2008; Ketz, 2008; Kumar, Grewal, Chung, & Bradley, 2009; McFarland, Choppa, Betz, Pruden, & Reiber, 2010; Melcer et al., 2010; Owens, Kragh, Macaitis, & Wenke, 2007; Smurr, Gulick, Yancosek, & Ganz, 2008; Stansbury, Lalliss, Branstetter, Bagg, & Holcomb, 2008). Thus, this feasibility study was undertaken to compare the quality of well-being and PTSD of military personnel following traumatic amputation.

Background and Significance

Regarding the management of casualties on the battlefield, recent events have focused attention on certain principles. Advances in military medicine and protective armor have factored into a greater percentage of wounded warriors surviving in the

OEF/OIF theater of combat. There is overwhelming evidence that the majority of survivable war injuries have been predominantly extremity injuries in all wars, but especially in the current conflict with the rules of engagement and environment. Mangled extremities have historically resulted in high amputation rates and mortality. In this war, there is a decrease in mortality rates due to the rapid evacuation and improved resuscitation. The type of combat engagement, use of IEDs, and protective armor has resulted in injuries that are primarily facial and extremity. Intensive care and the advent of arterial repair close to the battlefield allow for greater life and limb salvage. Complications (e.g., wound infections) are common requiring extensive intensive care, wound management, repeated surgeries, and one or more amputations. A significant number of soldiers return to the continental United States (CONUS) with traumatic injuries and limb loss (Fischer, 2009).

Post wounded soldiers are being evacuated to a treatment facility of their choice based on the type of injury and rehabilitation needs. As of 2010, there are three DOD-designated amputee centers; Walter Reed National Military Medical Center in Washington, DC; Brooke Army Medical Center in San Antonio, TX, and Naval Medical Center in San Diego, CA. Walter Reed Army Medical Center and Bethesda Naval Hospital have joined forces to care for amputees. These sites have allocated resources for the comprehensive care in rehabilitation and facilitating the injured soldiers' return to the highest possible quality of life with the option to be discharged or continue their military career (Amputee Coalition of America, 2010). Physical rehabilitation includes but is not limited to wound healing, prevention of complications, stump shrinking, fitting for prosthetics, and post-amputation ambulation. The opportunity for advancement of

military and civilian trauma care is unique given the types of injuries, age, health care status, and resources of the present day conflict.

Associated Assumptions Regarding this Study Area

This study area carries with it unique assumptions that must be considered in a feasibility study. The war effort is controversial, presenting a political, economic, emotional, psychological, and ethical dilemma. Assumptions are associated with multi-source communications, including the media, statements from politicians, the Internet, special reports, and documentaries. Assumptions are based on what is uncovered, discovered, and treated for the sake of a given discussion as if it were known to be true. Statistics of conflict include the number and types of injuries being reported regularly in print and on the radio, television, and the Internet. The war effort, soldier injuries, care, and rehabilitation are high profile news items. IED injuries are unique given the type of armor available for soldiers, resources (e.g., training, supplies), communication, and evacuation efforts. Traumatic amputations are common, but survival with devastating injuries is more common (Covey, 2008; Fischer, 2009)

Initial care of military personnel is essential, but only possible depending on the line of fire. Soldiers are equipped with military armor. The injuries sustained are largely due to the lack of armor for neck, limbs, and groin. The individual soldier has his own first-aid kit that includes a tourniquet, pill pack, and 14-gauge needle. Every vehicle is equipped with enough supplies to take care of four soldiers in event of an IED blast. The first, second, and third echelon of care is in the battlefield arena (Bagg, Covey, & Powell, 2006). Evacuation to the fourth echelon of care is the closest military hospital outside of the battlefield arena (i.e., Landstuhl, Germany) and the fifth echelon of care is CONUS.

Evacuation is swift; the average time from the front line to fourth echelon takes 24 to 72 hours, to CONUS in less than 1 week (Melcer et al., 2010).

As the war progresses, lessons are learned. The two major injuries accrued to date are traumatic amputation and traumatic brain injury (TBI). PTSD is common among all soldiers, even those without physical injury. The political/military issues are at the forefront of the public's mind with the media sharing the visibility of the military personnel issues, injuries, and essential care and rehabilitation. Multiple organizations have prepared to meet the needs of wounded warriors (e.g., Armed Forces YMCA, Wounded Warrior Project, Challenged Athletes Foundation, Army Warrior Transition Program, Veterans Administration). Wound care, wound infections, amputation rehabilitation, stump shrinking, prosthetics, and rehabilitation programs developed include psychological, physical, and emotional care. As issues are identified, programs are being designed specifically to meet the needs of those returning with injuries to facilitate rehabilitation and return to duty, a work/study program, or occupation (Seal, Bertenthal, Miner, Sen, & Marmar, 2007).

The diagnosis of PTSD is steadily increasing (Melcer et al., 2010; McFarland et al., 2010) especially in the military personnel with repeated deployments and extensions while in the combat theater. Physical, emotional, and psychological trauma are common among troops after experiencing hand-to-hand combat, living through repeated blasts, and watching others be killed, injured, and/or disfigured. Post-traumatic stress is at an all-time high as evidenced by the sheer numbers of military personnel accessing health care with a mental health diagnosis, drug and alcohol use and abuse, suicide rates, and recent reports of an increase in army desertion rates. Desertion has been related to a

sense of despair, hopelessness, and PTSD. The statistics for desertion have shown a steady increase over the past 4 years and a 42% increase from 2006 to 2007 (Seal et al., 2007). Army resources have had multiple extensions in combat and the challenges continue to mount as the war continues (McFarland et al., 2010). Nearly 10 years of war have taken a toll on the U.S. Army soldier. The U.S. Army suicide rates are at an all-time high. A 15-month study on suicide found 160 suicides among active-duty personnel, 1,713 suicide attempts, and 146 deaths due to high-risk behavior (e.g., drug abuse) in the year ending September 30, 2009. This increase in suicide rates were attributed to a combination of problems at home coupled with the stress of war, multiple deployments, and injuries. Thus, these underlying assumptions and sociopolitical context were taken into account in the analysis of these data. An evaluation of the barriers to feasibility of this study area are based on these factors and discussed in depth in Chapter 5.

Research Questions and/or Hypothesis

The purpose of this feasibility study was to examine the quality of well-being and PTSD of military personnel following traumatic amputation.

The *specific aims* were:

1. To describe the level of well-being (e.g., degree of mobility, physical/social activity, pain, anxiety, depression, anorexia, fatigue) and level of PTSD symptoms (e.g., degree of intrusive thoughts, intentional avoidance, hyperarousal) in a group of adult U.S. military personnel who suffered a traumatic amputation.

2. To describe relevant personal (e.g., age, gender, ethnicity), environmental (e.g., current living situation), and disability (e.g., number of amputations, location of amputations) factors in adult military personnel.
3. To examine the relationship between levels of well-being, PTSD symptoms, and relevant personal, environmental, and disability factors in a group of adult U.S. military personnel who sustained a traumatic amputation during combat or due to a military training accident.

The feasibility study sought to answer the following *research questions*:

1. What are the levels of well-being and PTSD symptoms in a group of adult U.S. military men and women who received a traumatic amputation during participation in OEF and OIF?
2. What are relevant personal, environmental, and disability factors in this group?
3. What is the direction and strength of the relationships among levels of well-being, PTSD symptoms, and relevant personal, environmental, and disability factors in a group of adult U.S. military-related men and women who received a traumatic amputation during participation in OEF and OIF?

Conclusion

This feasibility study was undertaken 7 years after the first military personnel were deployed. The military has learned an enormous amount in the area of IED soft-tissue injuries, evacuation, surgical procedures, and salvage of limbs, as well as amputation management. What had not been investigated was the post-recovery level and quality of function, especially with the incidence of PTSD after traumatic amputation. The researcher posited that gathering data specific to the quality of well-

being and comparing them with levels of PTSD would allow for advancement of scholarly work in the nursing areas of rehabilitation, psychiatry, and wound healing. Gathering data on demographics (e.g., personal, environment, disability factors) would isolate specific indicators for future programs, briefings, and insights into how intervention might be conducted prior to and after deployments. The data would enhance trauma nursing approaches and understanding for both military and non-military individuals losing limbs (e.g., motor vehicle accidents, IED blast injuries).

The opportunity for further research was unique due to limited study post injury and limited resources for nursing scholarly work, especially in the military arena. Conducting interviews and asking specific questions allows stories to be recounted, recorded, documented, and shared. This research would advance knowledge in military medicine as well as in civilian trauma centers. The development and validation of best practice guidelines for multidisciplinary care of the amputee are essential. In the context of current results and increasing levels of expectations for function following amputation, the development of more sensitive and militarily-appropriate outcomes measurement is necessary (Pollack & Calhoun, 2006). This study was intended to have been one of many studies to ensure that best practice guidelines are implemented and followed for maximum function and improved quality of life after traumatic amputation. Recognizing those with symptoms of PTSD and other personal, environmental, and disability indicators would allow for interventions with positive outcomes. However, as will be demonstrated in a discussion in Chapter 5, the feasibility of collecting these data is severely limited at present by systemic barriers.

Chapter 2

Literature Review

Introduction

Wounded warriors returning from OEF and OIF with traumatic amputation are experiencing specific issues with quality of life and PTSD. The purpose of this study was to measure the quality of well-being and impact of events in a group of adults who served in the U.S. armed forces and sustained the loss of one or more limbs during any combat or military training activity. The QWB-SA factors out functional ability, one component of a quality of life and measures mobility, physical activity, social activity, and symptoms experienced over time (e.g., pain, anxiety, depression, anorexia, fatigue). The IES-R factors out the most common symptoms of PTSD (i.e., intrusion of thoughts, intentional avoidance of thoughts, hyperarousal). Quality of well-being is closely related to the quality of life and is directly affected by the severity of PTSD, especially after traumatic amputation due to an IED explosion (Copuroglu et al., 2010).

Background and Significance

Military operations in Iraq and Afghanistan have resulted in a significant number of mangled extremities leading to traumatic amputations. Extremity injuries

predominate, representing 50% to 70% of all injuries treated during OEF/OIF. High-kinetic energy injuries, including those from IEDs, often cause soft-tissue, vascular, neural, and orthopedic destruction that leads to amputation. Local and systemic infections from resistant organisms, the number one complication of this injured population, leads to further damage and greater loss of limb, if not life (Melcer et al., 2010).

Traumatic limb loss due to a combat casualty present unique medical, surgical, and rehabilitation challenges as well psychological and emotional issues (Copuroglu et al., 2010). Healthy young male adults, averaging 26 years of age, who suddenly experience a catastrophic and unpredictable change in their health status are being tested with the capacity to cope and adapt. PTSD is on the rise, especially with repeated deployments and extensions in the combat theater. Physical, emotional, and psychological trauma is common among soldiers after dealing with hand-to-hand combat, experiencing violent acts, and watching others killed, injured, or disfigured (Copuroglu et al.; MacGregor et al., 2010). This is more significant due to increased numbers of military personnel being deployed, repeated and extended assignments, a combat environment with no discernable front line, and an opposition without military uniforms that includes children and women (Covey et al., 2008).

The majority of injuries sustained in OEF/OIF are combined penetrating, blunt trauma, burn and blast injuries, traumatic amputation, and infections from the multi-drug resistant organism, *Acinetobacter* (Melcer et al., 2010). The *CRS Report to Congress* (Fischer, 2009) confirmed that 31,934 soldiers in OEF and 8,040 soldiers in OIF have been wounded in action; 1,286 of those with amputations, 35% of which involve upper

extremity loss. Of these amputees, 935 suffered major limb loss and, in many cases, included multiple limb loss. As of March 2009, 39,365 soldiers were being treated for PTSD.

Advances in military medicine and use of protective armor translated into a greater percentage of the wounded surviving their insult. During the ongoing conflict in Iraq, the ratio of wounded to dead has been 10:1, whereas in previous wars this ratio was 3:1 (Gajewski & Granville, 2006). Evidence suggests that the majority of survivable war injuries have been predominantly extremity injuries in all wars, especially the current conflict. Mangled extremities have historically resulted in high amputation rates and mortality. Intensive care and the advent of arterial repair close to the battlefield allow for greater life and limb salvage (Bagg et al., 2006). Complications (e.g., wound infections) have been common, requiring extensive intensive care, wound management, repeated surgeries, and one or more amputations. Significant numbers of military personnel have returned to CONUS with traumatic injuries and amputations (Copuroglu et al., 2010; Covey et al., 2008; Melcer et al., 2010; Owens et al., 2007; Stansbury et al., 2008). The recent timing of the medical transport has improved, with as little as 24-48 hours to reach Landstuhl, Germany, and often less than 7 days to reach CONUS. With the Vietnam War, 15 days was the typical medical evacuation time from injury to a trauma center of excellence (Melcer et al., 2010).

The sequelae of these soft-tissue and musculoskeletal injuries were disability due to the extensive number of surgical procedures after major trauma. Phantom limb pain, wound infections, and poor self-image were common conditions after the initial injury and amputation. Amputees were commonly consumed by fear, depression, fear of

vulnerability, and crime. Vulnerability was the most significant predictor of post-amputation activity restriction when measuring quality of life and psychological maladjustment (e.g., PTSD; Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis, 2002). Depression and social isolation were common, especially if the emotional, psychological, and physical symptoms were not identified timely for intervention (Cavanagh & Karamouz, 2006; Copuroglu et al., 2010; Melcer et al., 2010).

Psychological Factors

Adaptation for this population involves the adjustment from a previously healthy self to a new, frailer self. According to Melcer et al. (2010), adaptation to a changed body image is a measure of psychosocial adjustment to amputation. Body image anxiety significantly relates to depression, lower level of self-esteem, higher levels of general anxiety, and lower levels of physical activity (Copuroglu et al., 2010; Melcer et al.).

Loss of a limb is a life-changing event that has psychosocial repercussions as equally devastating as the physical loss. Healthy soldiers who experience sudden catastrophic change in their health status from an external event, specifically an IED blast resulting in traumatic amputation, represent an extreme measure of one's capacity to cope with the severity, uncertainty, and probable PTSD (Copuroglu et al., 2010). Researchers indicated that the factors influencing an individual's reaction to trauma include the nature and severity of the event and the individual's ability to cope with the stress and trauma (Heppner et al., 2006; MacGregor et al., 2010). Coping includes the psychological impact of traumatic amputation; grieving over loss. Grieving includes processing and coping with denial, anger, blame, depression, and despair (Crichlow, Andres, Morrison, Haley, & Vrahas, 1933; Shear, 2010).

Wounded warriors must change, adjust, and adapt to the limb loss successfully to reintegrate into their families, peer groups, job setting, and/or return to duty (Amputee Coalition of America, 2010; Freeland & Psonak, 2007). The successful coping process is essential for a return to society as a whole. Heppner et al. (2006) identified five coping-style factors for effective reintegration: (a) acceptance, reframing, and striving; (b) family support, (c) religion/spirituality; (d) avoidance-detachment, and (e) private emotional outlets. Coping is essential for success but challenges those with PTSD. Positive coping allows for a successful outcome following traumatic limb loss (Schwarzer & Knoll, 2003). Factors that influence an individuals' reaction to trauma may relate to self-efficacy, sense of hopefulness, and having a strong internal locus of control.

Heppner et al. (2007) defined self-efficacy as the extent to which the client believed he/she was capable of performing required discrete rehabilitation skills. Those who did not have a strong internal locus of control were viewed as suffering from problems, such as learned helplessness, and deficit in self-efficacy (Heppner et al.; Weisz, Rothbaum, & Blackburn, 1984). Self-efficacy was the most important variable related to disability from pain (Copuroglu, et al., 2010; Jensen et al., 2006; Ketz, 2008) and self-efficacy beliefs were associated with better function and therapeutic coping strategies (Copuroglu et al., 2010; Dudgeon, Tyler, Rhodes, & Jensen, 2006). If an individual developed self-efficacy, (s)he was then capable of completing the required rehabilitation despite pain; if they believed they could, they actually performed.

Hope was characterized as “multidimensional and dynamic” (Dufault & Martocchio, 1985, p. 380), containing a confident yet uncertain expectation of achieving a future goal that, to the hoping person, was realistically possible and personally

significant. That in turn led an individual from despair to reconciliation (Penrod & Morse, 1997). Hope was defined as a personal and inner adventure that allowed for strength independent of context. Faith and hope were biblical expressions illustrating basic human needs, but willpower gave strength and energy to propel individuals to achieve rehabilitation goals after traumatic loss (Lohne & Severinsson, 2006). Hope was a life force, a prospective phenomenon with a future orientation, and a positive essence (Lohne, 2001).

Internal locus of control was innate and led to positive coping styles. Military personnel with an internal locus of control exhibited the ability to shape existing physical, social, and behavioral realities to fit their perceptions, goals, and wishes (Weisz et al., 1984). These personality traits allowed for successful re-integration, management of symptoms, and promotion of the subjective or actual quality of well-being for the individual. Internal locus of control exhibited naturally in those who successfully re-integrated with little or no PTSD or physical limitations, even after traumatic limb loss (Copuroglu et al., 2010; Koren, Norman, Cohen, Bermen & Klein, 2005).

Disablement Process Model (DPM)

Complex behavioral and neurological changes could follow a traumatic limb loss (Melcer et al., 2010). Soldier personality trait, strengths, and weaknesses could help predicted those who succumbed to PTSD and those who would return to a productive life with disability (Copuroglu et al., 2010). The DPM described the relationship between quality of well-being and the impact of events after traumatic limb loss. DPM was a sociomedical model built on the conceptual frameworks of Nagi (1991) and the World Health Organization (WHO; 2007). In this model, disability was defined as “a difficulty

doing activities in any domain of life due to a health or physical problem” (Verbrugge & Jette, 1994, p. 3).

The DPM was used to describe the process from disease or injury to social disability and described:

1. How acute conditions affected functioning in specific body systems, generic physical and mental actions, and activities of daily living, and
2. The personal and environmental factors that sped or slowed disability (i.e., risk factors, interventions, exacerbations).

It also identified needs, prevention of further injury, and promotion of re-integration considering physical, psychological, and emotional well-being.

Physical Factors

Pain is the leading cause of activity limitation and reduced participation (Dudgeon et al., 2006; Ketz, 2008; Melcer et al., 2010). Phantom limb pain and altered sensations are common post amputation and universally experienced among this population (Freeland & Psonak, 2007; Ketz; Melcer et al.). Ketz wrote that 77% of amputees reported phantom limb syndrome. Amputation and phantom pain influenced the physical and social well-being of the patient (Copuroglu et al., 2010; Ketz; Melcer et al.). Trauma patients experienced an increased frequency of physical and mental symptoms (Anderson & Holbrook, 2007; Melcer et al.). Physical symptoms included pain, gastrointestinal discomfort, fatigue, and anorexia. Mental symptoms included depression, trouble sleeping, anxiety, and thoughts of intrusion (Anderson, Stewart, & Unger, 2007; Guess, 2006; Melcer et al.). Pain had a negative effect on subjective well-being because it diminished comfort and hampered functional ability, forcing one to suspend activities and

causing severe psychological stress (Dudgeon et al., 2006; Melcer et al.). In a study by Anderson, Stewart et al., pain after amputation was common and disabling in 10% to 25% of the participants. In a study of 382 combat amputees, Melcer et al. reported that 55.5% of the amputees experienced phantom limb syndrome; the second most common complication of wounded warriors with limb loss.

Behel et al. (2002) conducted a study on perceived vulnerability in adjusting to lower extremity amputations. Eighty-four patients with a lower extremity amputation in five affiliated prosthetic clinics were investigated using the Center for Epidemiologic Studies Depression Scale (CES-D), a three-item quality of life measure and a two-item vulnerability measure. The themes revealed altered body image, avoidance, depression, anxiety, social isolation, activity restriction, quality of life issues, and fear of crime. Results indicated that, as social discomfort increased, social support decreased with perceived health and depression following amputation. Gallaher, Horgan, Franchignoni, Giordano, and MacLachlan (2007) found an increased vulnerability with obvious disability due to the amputation; fear for safety and of crime prevailed.

The disablement process specifically aligns with the QWB-SA and the IES-R. These two instruments measure the extent of mobility, physical and social activity, physical and mental signs and symptoms of injury, and PTSD that interfere with activities of daily living. Returning wounded warriors are challenged to adapt to their disability and believe they can continue their life as a productive, functioning member of society with their disability. Restoring a sense of continuity requires addressing normalizing ideologies and its effect on one's life. One may need to redefine normalcy after a disruption (Becker, 1997).

Environmental Factors

Multiple characteristics of the individual and his or her environment influenced the prevalence of conditions that affected function and quality of life. The social/work environment was an important concept in relation to the soldier's quality of well-being and PTSD. Some of the characteristics included current living conditions, perceived and/or actual physical barriers, level of education, and social support. Returning to duty or a paid job played a positive role in well-being (Amputee Coalition of America, 2010; Bonanno, 2004; Gajewski & Granville, 2006; National Center for Post-Traumatic Stress Disorder & Walter Reed Army Medical Center, 2004). In one study of post-traumatic limb loss, 80% of those injured returned to driving 3.8 months after amputation, allowing for independence and autonomy (Bosmans et al., 2007).

Social Factors

Communication with family and friends about the major life changes that had occurred were necessary for successful coping and adaptation. Having meaningful roles, activities, and/or the support of family and friends related to patients' satisfaction in life (Copuroglu et al., 2010; Melcer et al., 2010). Returning to a revenue-generating role increased the quality of well-being. In the Anderson, Stewart et al. (2007) study, only 58% of patients with trauma-related amputations returned to work within 2 years of the injury. The ability to return to work directly related to a more distal amputation, fewer days in the hospital, and higher income. Factors associated with greater disability included increased age, number of surgical procedures, number of days in the hospital, and more proximal amputation. Early return to work or duty might be instrumental to recovery (Freeland & Psonak, 2006). Amputees from OEF/OIF had been granted the

choice to return to full active duty, including combat, be retrained into another role within the military, or separated from the military and into civilian life (American Coalition of America, 2010; Melcer et al.).

Emotional Factors

PTSD is highly correlated with patients who felt emotional problems caused by the injury where coping was more difficult than the physical problems. Emotional problems included flashbacks, insomnia, nightmares, affective lability, loss of body-image and self-worth, depression, concentration and attention problems, preoccupation with phantom limb sensation, cosmetic concerns, and fear of death (Copuroglu et al., 2010; Freeland & Psonak, 2007). In an early study conducted by Grunert, Smith, and Devine (1988), results indicated that 2 months after amputation, flashbacks and affective disorder often persisted and phantom sensation and cosmetic concerns increased. PTSD was directly related to the soldiers who had the most combat exposure and was associated with military service-related mental health disorders (Copuroglu et al.; MacGreagor et al., 2010).

Post-Traumatic Stress Disorder (PTSD)

The quality of well-being directly relates to the symptoms and severity of PTSD. In the *Diagnostic and Statistical Manual of Mental Disorders – Text Revised* (4th ed.) (DSM-IV-TR), PTSD is defined as having interfering thoughts (e.g., nightmares, flashbacks), sleep disturbances, an amplified startle response, high levels of psychological distress, physiological responses to stimuli that remind the person of the trauma, and cognitive as well as memory disturbances associated with avoidance of trauma-related stimuli (American Psychiatric Association, 2000; Copuroglu et al., 2010;

Melcer et al., 2010). The diagnosis of PTSD requires that one or more symptoms from each of the following categories be present for at least 1 month and that symptom(s) must seriously interfere with leading a normal life:

1. Reliving the event through upsetting thoughts, nightmares or flashbacks, or having very strong mental and physical reactions if something reminds the person of the event;
2. Avoiding activities, thoughts, feelings, or conversations that remind the person of the event; feeling numb to one's surroundings; or being unable to remember details of the event;
3. Having a loss of interest in important activities, feeling all alone, being unable to have normal emotions, or feeling that there is nothing to look forward to in the future;
4. Feeling that one can never relax and must be on guard all the time to protect oneself, trouble sleeping, feeling irritable, overreacting when startled, angry outbursts, or trouble concentrating (American Psychiatric Association, 2000).

PTSD occurs when military personnel experience, witness, and/or are confronted with an event that involves actual or threatened death, serious injury, or threat to physical integrity. The response involves intense fear, helplessness, or horror. The disturbance causes distress and impairment in societal, occupational, and other areas of functioning that last more than 1 year (Cavanagh & Karamouz, 2006; Copuroglu et al., 2010; Freeland & Psonak, 2007). In one study of 103,788 soldiers seen at the Veterans Affairs health care facilities, 25% of patients received a mental health diagnosis (Seal et al., 2007). In more recent studies, 18.1% reported PTSD (Melcer et al. 2010) and 77.2%

reported PTSD as a chronic and delayed response after traumatic limb loss in combat (Copuroglu et al., 2010). More than 50% had two or more distinct mental health care diagnoses, with the youngest group (age 18-24 years) at greatest risk of receiving mental health or PTSD services (Seal et al.). PTSD was the single most common mental health diagnosis with complex behavioral issues following an isolated stressful event.

Flashbacks were common and likely to persist in patients with occupational injuries resulting in limb loss. PTSD was also the strongest predictor of an adverse outcome 1-year after injury (Copuroglu et al.; MacGregor et al., 2009; Melcer et al.).

Although a worldwide problem, PTSD currently affects a sizable proportion in the United States due to war, abuse, violence, and natural disasters (Shear, 2010).

Approximately 25% of all individuals that experience a traumatic event as described by the American Psychiatric Association (2000) will develop PTSD (Guess, 2006; Schnurr, Friedman, & Bernardy, 2002), including 70% of veterans (Shear). With PTSD, individuals are identified with failure to organize, failure to sense internal locus of control, failure to adapt, failure to cope, failure to have faith and or believe that they can succeed; common characteristics of the military personnel returning with traumatic limb loss. Negative consequences are common if PTSD is either misdiagnosed or there is lack of recognition due to ineffective management, poor compliance, miscommunication, and inadequate response to treatment (Guess).

Summary of Literature Review

Many studies have been conducted on PTSD (Copuroglu et al., 2010; Guess, 2006; Seal et al., 2007), quality of well-being (Anderson & Holbrook, 2007; Bosmans et al., 2007; Dunn, 1996; Holbrook, Hoyt, Anderson, Hollingsworth-Fridlund, & Shackford,

1994), and the psychological effects of traumatic injury (Cavanagh & Karamouz, 2006; Copuroglu et al.; Freeland & Psonak, 2007; Graham, Parke, Paterson, & Stevenson, 2006; MacGregor et al., 2010). One specific study has been published on combat amputees and common post amputee conditions in relation to traumatic limb(s) loss using various military databases (Melcer et al., 2010). The theoretical framework of DPM allows this study to consider the factors relating to the injury, functioning, physical and mental symptoms, activities of daily living, and psychological well-being. The instruments QWB-SA and IES-R factor the same concepts and relationships in an effort to correlate findings for greater knowledge and understanding.

Much research is needed to complement the understanding and knowledge for the care of wounded warriors returning after traumatic limb loss from OEF/OIF. There are gaps in knowledge from the present-day conflict, particularly the relationship between quality of well-being and PTSD symptoms (Melcer et al., 2010; Pollack & Cohen, 2006).

Importance to Advancement of Knowledge, Nursing Science, and Practice

This study was designed to provide critical data for future interventional studies to prevent chronic mental illness and promote quality of well-being among OEF/OIF military personnel with traumatic limb loss (Melcer et al., 2010; Seal et al., 2007). An increase in the number new cases and unresolved treatment may lead to chronic, costly, logistical, and fiscal challenges, both for the Veterans Administration and non-VA mental health providers. This investigation proposes to deepen understanding of the traumatic limb loss experience and the resultant quality of well-being secondary to PTSD. Lower-extremity amputation in the United States is greater per capita than any other developed nation, primarily due to the ongoing armed conflict in OEF/OIF. A study examining

quality of well-being and PTSD status after traumatic limb loss is relevant (Anderson, Stewart et al., 2007; Melcer et al.; Owens et al., 2007; Stansbury et al., 2008).

Use of Research Evidence

Multiple studies suggest that rehabilitation programs should be initiated within the first week of amputation (Copuroglu et al., 2010; Freeland & Psonak, 2007; Melcer et al., 2010). Early intervention improves outcomes, minimizes psychological trauma, decreases morbidity, and facilitates successful and sustained return to active duty or other productive activity.

Insights captured from those who have had a traumatic limb-loss in reference to quality of well-being, functional ability, and PTSD are expected to be particularly helpful to others with disabilities and practitioners who care for them. Information from conducting this feasibility study is valuable for health care providers in both the military and civilian sectors as well as for those who have experienced a traumatic injury. In conducting this feasibility study, information learned will be valuable for future research objectives for those who are affected, both physically and psychologically.

Conclusion

Given the current gaps in knowledge, this study proposes to fill a valuable need at an opportune time. This study was designed to contribute to the body of knowledge specifically on how U.S. service men and women injured in combat are surviving with traumatic limb loss (Becker, 1997).

Chapter 3

Methods

Introduction

This chapter explores the plan, approach, and attempts to enroll participants into this feasibility study. While this study was intended to investigate the quality of well-being and impact of event after a traumatic limb loss, in any combat or military training accident, its feasibility became increasingly limited. A description of the attempts to elicit interest and enroll subjects as a basis for further discussion of the feasibility of this study area is provided in Chapter 5.

In December 2008, the University of San Diego's Institutional Review Board granted permission to start enrolling soldiers, airmen, sailors, and Marines into a study investigating quality of life after a traumatic limb loss. It was at the height of Operation Enduring and Iraqi Freedom (OEF/OIF). Men and women were losing limbs due to improvised explosive devices and returning to the United States to adapt their lives. This study of emotional and physical adaptation was considered to be nationally important, politically necessary, and practical to study. The public expresses sincere interest in the welfare of the injured military member and the underlying issues revealed in this report.

Military and civilian colleagues involved in developing the design of the study felt the outcomes would contribute to the scholarly work of nursing, medicine, and rehabilitation.

Research Question and Hypothesis

The overall purpose of this study was to explore quality of well-being, levels of PTSD symptoms, and relevant personal, environmental, and disabling factors in a group of adult U.S. men and women who suffered a traumatic amputation with their participation in combat or during a military training accident.

The specific aims of this study were:

- 1) To describe the level of well-being (e.g., degree of mobility, physical/social activity, pain, anxiety, depression, anorexia, fatigue) and level of PTSD symptoms (e.g., degree of intrusive thoughts, intentional avoidance, hyperarousal) in a group of adult U.S. military personnel who suffered a traumatic amputation.
- 2) To describe relevant personal, environmental, and disability factors in adult military personnel, specifically personal factors (e.g., age, gender, ethnicity); environmental factors (e.g., current living situation); and disability factors (e.g., number of amputations, location of amputations).
- 3) To examine the relationship between levels of well-being, PTSD symptoms, and relevant personal, environmental, and disability factors in a group of adult U.S. military personnel who sustained a traumatic amputation during combat or military training accident.

This study sought to answer the following research questions:

1. What are the levels of well-being and PTSD symptoms in a group of adult U.S. armed forces men and women who received a traumatic amputation during participation in combat or military training accident?
2. What are relevant personal, environmental, and disability factors in this group?
3. What is the direction and strength of the relationships among levels of well-being, PTSD symptoms, and relevant personal, environmental, and disability factors in a group of adult U.S. men and women who received a traumatic amputation during participation in combat or military training accident?

It is hypothesized that:

H₁: Level of well-being will be negatively correlated with level of PTSD symptoms.

H₂: Level of well-being will be positively correlated with personal factors.

H₃: Level of well-being will be negatively correlated with environmental factors and disability factors.

The purpose of this study was to measure the quality of well-being and impact of events in a group of adults who served in the U.S. armed forces and sustained the loss of one or more limbs during any combat or military training activity.

Research Design

A descriptive correlational cross-sectional design was used for this study. This research design was appropriate to assess the factors that affected quality of well-being after traumatic limb loss (Polit & Hungler, 1991). The methodology included use of instruments (i.e., standardized measures) and a structured demographic form (see Appendix A).

Sample and Setting

Data were collected in person and electronically. Preference to type of encounter and location was at the discretion of the potential participant. Hindrances to the researcher conducting interviews in person were geographic location, timing, and costs. Every effort was made to meet the soldier/participant in person. Meeting locations were conducted at the place of employment. The data collection instruments and demographic data collection form were designed to be self-administered and could be completed individually.

The sample was recruited through service organizations e.g., Wounded Warriors, amputation support groups, Amputee Coalition of America, civilian and military wound care colleagues). A recruitment flyer (see Appendix B) describing the study and inclusion criteria was distributed to encourage participants to volunteer. The flyer included the nature of the research, assurances of confidentiality, and contact numbers for PTSD assistance. Data collection instruments and the demographic form were distributed electronically and collected personally. All study data were de-identified to protect unintended disclosure of participants' responses. Source documents were stored in a double-locked environment.

Power Analysis and Sample Size

An estimate of the number of participants needed to adequately power this study was calculated using G*Power (Faul & Erdfelder, 1993) with a power of .80, effect size of .90, and alpha level of significance at .05 using a two sample *t*-test (2-tailed) study. A sample size of 42 participants was indicated in order to achieve the desired power.

Inclusion criteria included:

1. Any active, reserve, or prior service U.S. armed forces men and women who were at least 18 years old.
2. Sustained one or more traumatic limb loss in any theater of combat or military-related training accident.
3. Expressed willingness to participate and consented to study.

Exclusion criteria included:

1. Those with altered mental status due to traumatic brain injury.
2. Soldiers with injuries sustained within the last 12 months.

Protection of Human Subjects

Institutional Review Board approval (see Appendix C) was obtained through standard procedures at the University of San Diego. An expedited review was requested and approved as the study did not include an intervention. A plan was developed specifically to address any risks before, during, and after data collection. Participation in research involved minimal risks, including the possibility of negative emotions (e.g., sadness, anxiety, intrusive thoughts, flashbacks). Potential risks were disclosed in the informed consent (see Appendix D). Although this was strictly a data collection study, completion of the instruments and questionnaire might cause participants to experience anxiety or other negative emotions. To reduce the risk of anxiety, data collection tools were administered in a setting of the soldier's choice where the participant completed the questions without fear of interruption or observation. Participants were advised to omit or skip over any objectionable question. Additionally, participants were instructed in both the informed consent and by the researcher that they can stop the study at any time or could resume at another time or location. Once the data collection tools were

completed, the forms were placed in an envelope labeled with a unique participant identifier known only to the investigator. The investigator analyzed the results at a later time in a private setting.

Data Collection Instruments/Measures

Quality of Well-Being Scale-Self Administered (QWB-SA). The QWB-SA was developed in response to previously identified limitations in the QWB Scale, originally developed in the 1970s as a comprehensive measure of health-related quality of life (Kaplan, Bush, & Berry, 1976). It is a general health-related quality of life questionnaire measuring paths of change in health status over time. The QWB-SA, a 71-item tool, combined three scales (i.e., mobility: physical activity, social activity) with a measure of symptoms/problems. Seven studies in differing populations reported high reliability using the QWB-SA, with scores ranging from .83 to .98 (Kaplan, Ganiats, Sieber, & Anderson, 1998). Reliability was also reported in test-retest reproducibility (Anderson, Kaplan, Berry, Bush, & Rumbaut, 1989) and for internal consistency (Anderson, Bush, and Berry, 1988). The overall QWB-SA score is calculated using a preference-weighted average of functioning in the previous 3 days with respect to symptoms and the three function scales. The instrument can be completed in 12-20 minutes.

The validity of the measure has been well established and both the sensitivity and predictive value independent of the measure have been estimated above 0.90 (Holbrook, Hoyt, Stein, and Sieber, 2001). Content validity was reported and demonstrated through correlations with chronic conditions and symptoms (Kaplan, Bush et al., 1976). The QWB-SA has been a widely applied measure in health outcomes research, combining

preference-weighted measures of functioning with symptoms/problem complexes (CPX). It measures social activity, physical activity, mobility, and symptoms, including pain, anxiety, depression, fatigue, and anorexia. The QWB–SA will accurately represent changes that occur over a brief time on a scale from 0.0 (death) to 1.0 (asymptomatic or fully functioning) along with points in between (Anderson & Holbrook, 2007). At a given moment, the QWB–SA comprises one symptom weight (CPX) and three dysfunction weights (DYS).

Impact of Events Scale – Revised (IES-R). The IES-R is designed to assess symptoms of PTSD, specifically the three subscales (i.e., intrusion of thoughts, intentional avoidance, hyperarousal). A 22-item instrument, the IES-R measures intrusion, factoring out the degree of persistent re-experience of the trauma, avoidance to the degree of psychological defense against re-experience, and hyperarousal. The goal with management of PTSD is to maintain emotional balance and prevent overwhelming emotions (Gustafsson & Ahlstrom, 2004). This instrument identifies high levels of traumatic stress symptoms (Horowitz, 1982). The IES–R is a self-reported measure designed to assess current subjective distress for any specific life event (Weiss & Marmar, 1997). Respondents are asked to rate each item experienced in the last 7 days on a scale ranging from 0 (*not at all*), 1 (*a little bit*), 2 (*moderately*), 3 (*quite a bit*), and 4 (*extremely*).

Weiss and Marmar (1997) reported high internal consistency of the three subscales with intrusion alphas ranging from .87 to .92, avoidance alphas ranging from .84 to .86, and hyperarousal alphas ranging from .79 to .90 (Briere, 1997). Test-retest reliability was available for two samples in Weiss and Marmar and yielded the following

test-retest correlation coefficients for the subscales: (a) intrusion = .57, avoidance = .51, and hyperarousal = .59 ($n = 429$), and (b) intrusion = .94, avoidance = .89, and hyperarousal = .92 ($n = 197$). Weiss and Marmar believed that the shorter interval between assessments and the greater recency of the traumatic event in the second sample contributed to the higher coefficients of stability that supported investigating the length of time since injury and excluding those injured within the last 12 months.

Weiss and Marmar (1997) noted that the hyperarousal subscale had good predictive validity with regard to trauma (Briere, 1997). The intrusion and avoidance subscales were shown to detect changes in respondents' clinical status over time and relevant differences in response to traumatic events of varying severity. For construct validity, Weiss and Marmar utilized the item-to-subscale correlation with items removed from the subscale generated by the standard alpha coefficient analysis.

The QWB-SA and IES-R are questionnaires may be self-administered or completed using an interview process. Researcher-guided data collection was optimal for completeness and clarity. Every effort was made to have researcher assist in the completion of instruments, especially if the participant preferred and mutually agreed to a designated date, time, and location. The goal of this study was to describe the phenomena of traumatic limb loss and quality of well-being in relationship to symptoms of PTSD. This descriptive prospective study had seven subscales:

- Mobility
- Physical activity
- Social activity
- Symptoms/CPX – pain, anxiety, depression, anorexia, fatigue

- Intrusion of thoughts
- Intentional avoidance
- Hyperarousal

Demographic data questionnaire. The demographic form was one-page and included 10 items to describe physical, disability, and environmental factors, five items specific to the physical factors (e.g., age, gender, ethnicity), two items to describe the disability factors (i.e., number of amputations, location of amputations), and three items to describe the environmental factors (i.e., physical living quarters, current living situation, social/work situation). One section of the form offered the participant an opportunity to add any comments, concerns, or ideas in reference to this study, the concepts being explored, and/or personal feelings (see Appendix A).

Procedure

Recruitment. Participants were recruited via networking groups focusing on wounded warriors, wound care, and management of amputations. Additional referrals were elicited from amputation support groups, wound care forums, and chat rooms. Increased visibility was accomplished within the military community by visiting rehabilitation centers, posting flyers in newspapers, magazines and wound care conferences, and soliciting other organizations that serve wounded warriors. The Human Subjects Protection Committee and Institutional Review Board reviewed all study-related recruitment and educational materials for approval before use.

Data collection procedure. Once a participant was identified as meeting all criteria for inclusion and willing to participate, the informed consent was signed. A participant information sheet was offered to read and discuss the specific aims, procedure

for data collection, and points of contact for either follow-up and/or counseling services, if desired. The *Coping with traumatic stress reactions: A National Center for PTSD fact sheet* (Swales, n.d.) was available and offered to every participant enrolled in the study. The instruments were designed to be self-administered, completed, and returned to the researcher. Both the participant and researcher agreed upon the location of the testing. Each testing session took less than 60 minutes. Once the data collection tools were completed, the forms were placed in an envelope labeled with a unique patient identifier known only to the investigator. The investigator analyzed the results later in a private setting.

Data Management and Analysis Plan

The management and analysis of all survey data was conducted, including demographic data from the sample. Limitations and strengths were ascertained and discussed after the data was collected. Descriptive analyses were conducted with demographic indicator as identified (e.g., age, number and severity of amputations, current living situation). Correlational analyses were considered for factors that trend for the QWB-SA or symptoms of PTSD. The Statistical Package for the Social Sciences (SPSS, Version 12.0) was utilized to analyze descriptive statistics, such as the mean, mode, median, variance, standard deviation, and range. Tables are utilized to describe the variables.

Descriptive Statistics for Demographic Data

The basic features of this study were to analyze data into simple summaries about the sample. The plan was to do an analysis using a frequency distribution bar chart, histogram, or table for age, gender, ethnicity, and rank/rate to describe the participants.

This analysis was to answer the question in relationship to the relevance of personal, environmental, and disability indicators in the group of adult U.S. men and women who participated in the study. Frequency distributions and measures of central tendency were performed to describe an estimate of the dispersion of data, where appropriate (Hinkle, Wiersma, & Jurs, 2003). The scores were inputted into SPSS.

Correlational Data Analysis

Even though correlational data analysis does not determine a causal relationship, a positive or negative association can be detected when factoring indicators and instrument measure outcomes. Once bivariate comparison is completed, significant factors can be incorporated into a multiple regression analysis to determine the degree of predictability that may exist for QWB and PTSD. In other words, this analysis would explore the extent to which QWB and PTSD might be explained by precipitating events and pre-existing factors.

Chapter 4

Results

Introduction

This study strove to investigate the feasibility of collecting data on the quality of well-being and impact of event after a traumatic limb loss in any combat or military training accident. A generalized description of the data from the three subjects who were enrolled is presented but detailed information omitted to maintain confidentiality and protect anonymity. Subsequently in Chapter 5, a description of the attempts to elicit interest and enroll subjects is given as a basis for further discussion of this study area.

Demographic Data

Three males, all-active duty enlisted at the time of injury, sustained a limb loss and agreed to participate in this study. The age range was 27-45 with a mean of 37.33 years (SD = 9.03). There were two Caucasians and one Hispanic; two were Army and one Marine Corps. They served from 1 to 19 years with a mean of 7.6 years (SD = 9.10). Two of the enrollees sustained a lower limb loss in OEF/OIF due to IEDs and one study participant lost an upper limb due to military vehicle accident (see Table 1).

Table 1

Demographic Characteristics of the Sample (n = 3)

| | <i>Frequency (Range)</i> | <i>Mean</i> |
|-------------------------|------------------------------|-------------|
| Age | (27-45) | 37.33 |
| Male | 3 | |
| Female | 0 | |
| Race/Ethnicity | | |
| White/Caucasian | 2 | |
| Hispanic | 1 | |
| Enlisted | 3 | |
| Officer | 0 | |
| Active Duty | 3 | |
| Reservist | 0 | |
| Year/s Served Range | (1-19) | 7.6 |
| Amputations (each) | 1 | |
| Below knee | 0 | |
| Above knee | 2 | |
| Below elbow | 1 | |
| Above elbow | 0 | |
| Dominant | 2 | |
| Non-Dominant | 1 | |
| Environment | | |
| Single Family Home | 2 | |
| Apartment | 1 | |
| Live Alone | 1 | |
| Live with Spouse | 1 | |
| Live with Spouse/Family | 1 | |
| Employed | | |
| Fulltime | 3 | |
| Other | | |
| Mech. Of Injury | | |
| IED | 2 | |
| Accident | 1 | |
| Date of Injury | | |
| 2006 | 1 | |
| 2005 | 1 | |
| Before 2005 | 1 | |

All three of the study participants were full-time employees, drove their own cars, and used prosthesis. One was still on active duty. Two subjects lived in single family homes - one with a spouse and one with a spouse and children; another lived alone in an apartment. Two of the three stated that their ideal living environment would be at home with family, the other stated, "to win the lottery." The three felt that data was missing from the questionnaire, so they added information verbally or in writing. The date of injury, reason for loss of limb, and whether it was the dominant or non-dominant side of the body was important to each of these respondents when completing the quality of well-being instrument.

Impact of Event – Revised Scale

The IES – R is an instrument designed to assess symptoms of PTSD, specifically the three subscales of intrusion of thoughts, intentional avoidance, and hyperarousal. Intrusion factors out the degree of persistent re-experience of the trauma, avoidance to the degree of psychological defense against re-experience, and hyperarousal. Respondents are asked to rate each item experienced in the last 7 days on a scale ranging of 0 (*not at all*), 1 (*a little bit*), 2 (*moderately*), 3 (*quite a bit*), and 4 (*extremely*).

The result for study respondents for each of the subscales is reported. The range of responses for intrusion of thoughts was from zero to 3.2 with a mean of 1.13, indicating a low level of difficulty with intrusion of thoughts. Intentional avoidance of re-experience results ranged from zero to 2.4 with a mean of 1.26, also indicating a low level of difficulty with intentional avoidance. Hyperarousal results ranged from zero to 2.4 with a mean of 0.8, reflecting slight or no difficulty with hyperarousal. The total score in each category ranged from 0-16 for intrusion of thoughts, 0-12 for avoidance,

and 0-12 for hyperarousal. The total scores collectively were from 0-40 and a median of 9.5, and a standard deviation of 20.89 (Table 2).

Table 2

Results of Impact of Events Scale – Revised (IES-R)

| | <i>Subject 1</i> | <i>Subject 2</i> | <i>Subject 3</i> | <i>Mean</i> |
|--------------|------------------|------------------|------------------|-------------|
| Intrusion | 3.2 | 0.2 | 0 | 1.13 |
| Avoidance | 2.4 | 0 | 1.4 | 1.26 |
| Hyperarousal | 2.4 | 0 | 0 | 0.08 |

Quality of Well-Being – Self Administered Scale

The QWB-SA Scale is a general health-related quality of life questionnaire measuring paths of change in health status over time. The overall QWB-SA score is determined based on a preference-weighted average of functioning in the previous 3 days with respect to symptoms and the three function scales. The QWB - SA is a widely applied measure in health outcomes research and combines preference-weighted measures of functioning with symptoms/problem complexes (CPX). It measures social activity, physical activity, mobility, and symptoms, including pain, anxiety, depression, fatigue, and anorexia. There are 18 function limitations, 26 symptoms/problem complexes, and 11 dysfunction descriptors and scale steps to determine level of well-being (see Appendix K).

Three to four function limitations were recorded for each participant with the QWB-SA instrument. Limitations recorded were limb loss, use of a prosthesis, hearing loss, deformity or burn, and use of eyeglasses or contact lenses.

Of the 26 physical and mental symptoms or problems listed, these study participants recorded a range of 6-12 each. Headache, feelings of frustration, and use of over-the-counter medications were recorded more than once. Other symptoms were dizziness, toothache, chest pain, nausea, difficulty with bowels or rectal pain, and pain in neck and hips. Mental health symptoms included trouble falling asleep or staying asleep, excessive worry, feelings of frustration, feelings of no control over life events, and feelings of isolation or being lonely.

The 11 dysfunction descriptors include an assessment of mobility, physical activity, and social activity. The possible score range is 0-15, with results at 11-15. All three respondents scored the highest in the mobility category, as they were all able to drive their own vehicles and use public transportation. In the physical activity category, two recorded 3 of 4 on the scale as they were limited in walking due to limping, using a prosthesis, in a wheelchair, or having difficulty bending over or not able to walk as fast as others. In the social activity category, one subject recorded a 3 of 5 on the scale as limited in a major role activity. This respondent was limited in doing some of the usual activities or needed assistance. Limitations included visiting family, hobbies, shopping, participating in recreational, and religious activities. All three points in time recorded (i.e., yesterday, 2 days ago, 3 days ago) were listed as having had to change plans or activities because of health.

Summary of Results – Limitations of the Study

The small sample size limits the generalizability and appropriateness for inferential statistical analysis, although they do provide information for future case studies. Nevertheless, the extraordinary efforts to recruit subjects with limited results

constitute a basis for discussing the feasibility of the study and planning for future work in this area as addressed in Chapter 5.

Chapter 5

Discussion

Summary

This study sought to investigate the quality of well-being and impact after a traumatic limb loss in any combat or military training activity. Since the investigator was unable to complete the planned study due to insufficient enrollment, the following discussion suggests barriers in obtaining study participation. The next section describes the extraordinary efforts made to recruit subjects, followed by the uses of Yin's (2009) framework to explore related rival explanations contributing to the feasibility of study completion. Lastly will be a discussion about the implication for future research.

Process of Enrollment Attempts

The following narrative presents the exhaustive efforts used to enroll participants, including each lead, opportunity, and potential prospect. Each of the approaches is described individually.

As a Lieutenant Colonel in the U.S. Army Reserves and registered nurse specialized in wound care, foot care, and amputations, the investigator was well qualified and positioned to complete this study. The many resources available included forums

with advanced practice clinicians in both military and civilian arenas and opportunities for podium presentations to groups of physicians, nurses, and therapists. The initial approach was to distribute the notification of Institutional Review Board-approved flyer electronically, delineating the topic, inclusion and exclusion criteria, and point of contact information to those interested in assisting with study enrollment. Early on, there were numerous discussions, genuine interest, referrals, and encouragement. Colleagues from across the United States made recommendations and linked the investigator to potential participants with assurances that there were many prospects who could complete the study questionnaires and return them with the requested consent. The Wound Ostomy Contenance National Forum was a sounding board for discussion as to the feasibility of study enrollment and anticipated participation.

Summary of Efforts to Enroll Study Participants

Conference attendance, presentation, and networking. As the investigator is a national speaker in the areas of skin, wound, foot care, and amputation management, invitations were received to present the research topic. The study was presented to small audiences, including Family Health Care of the Veterans Administration (VA) of Richmond, CA, and to larger audiences at the annual Wound Care Conference of Sharp Rees Steely, San Diego, CA. Each invitation was accepted to broaden dissemination of enrollment in the study.

An Army nurse practitioner at the VA of Richmond organized a retreat for the Family Health Department and requested this study proposal as the keynote address. At that time, the investigator believed the VA would be receptive to this study. The Prevention of Amputation coordinator (PACT) who monitors traumatic limb loss, would

be at the retreat to hear about the study. Given the initial response to the study, the expectation was that these key individuals and organizations would contribute to the success of the study by identifying potential research subjects. Other invitations to speak about this research study and the need for participants were received from the Pacific Coast Regional Wound Care Nurses Conference in Oakland, CA; Physician Assistant Wound Care Conference at Travis Air Force Base, CA; and the 9th Battalion, 4th Brigade, 100th Division Combat Medic/Nurse Instructors Workshop in Dublin, CA. After every podium presentation, audience members approached the investigator to further discuss the study topic and suggestions for recruiting participants. Many expressed knowledge of individuals meeting study criteria and promised to forward information about enrolling. No subjects were recruited from any of these speaking engagements.

One highlight was the invitation to speak at the 10th Annual Sharp Wound Care Conference in San Diego, CA. Attendants included 270 clinicians from the local medical community there to learn about advanced wound care therapies, specifically care of the military. The audience's response was favorable – some were in tears from the stories of soldier injuries and PTSD issues – and the study received enthusiastic support. That presentation led to other speaking engagements at the California Department of Health Services workshop and at the California of Hospital Foundations Conference, both in San Diego, CA. At last two audiences were focused on the older population issues, not necessarily military concerns; therefore, there was little opportunity to encourage study participation.

Another notable lecture was the invitation by Walter Reed National Military Medical Center to be a speaker at the Annual Wound/Foot Care Conference to address the issues entitled, *Foot Care in the Field*, and the importance of therapeutic foot care and foot wear with military personnel. There was time to discuss the study topic, inclusion/exclusion criteria, and encourage participation. Interest in the topic was generated as the audience included military personnel and Department of Defense employees. Again, suggestions were offered and promises made to contact those meeting inclusion criteria; however, no referrals or enrollees ever resulted.

To reach a larger, politically-focused arena, an application was made to the National Nurse in Washington Internship; a 4-day event for registered nurses from all of the American Nurses Association Specialties. The study topic was presented to 124 nurses from all specialties and the need stressed for enrollment. There was open dialogue about military personnel in the VA HealthCare System and protection of those that were wounded. This particular group offered to return to their respective facilities with study documents and inquire about those with limb loss for study enrollment. No referrals were received or study participants recruited as a result of this event.

Abstracts, entitled *Wound Care at the Frontline: Tactical Combat Casualty Care*, were submitted and accepted at several wound care conferences for dialogue about the feasibility of enrolling participants with traumatic limb loss and PTSD. On one such occasion, a high-ranking active duty wound care nurse based at Brooke Army Medical Center approached the poster, asking many questions. He volunteered to be the champion for advocating and encouraging study enrollment at the Center of the Intrepid,

a center of excellence for the care of amputees in San Antonio, TX. After several months with continued electronic follow-up, there were no study participants forthcoming.

Presentations at conferences were a deliberate attempt to share information and reach a greater number of individuals at one time. The conferences were focused on issues pertinent to this study, consistently resulting in promises that study participants would be contacted and information forwarded for study enrollment. In total, the investigator gave 69 presentations. More than 1,300 audience members attended using this approach, but not one participant was enrolled.

Organization networking and volunteering. Before approval from the Institutional Review Board at the University of San Diego was granted, efforts on the investigator's part were made to develop relationships with organizations who were offering support services to wounded warriors. The objective was to search for and participant in events for wounded warriors. The San Diego Adaptive Sports Foundation, Wounded Warrior Project, National Association of Mental Illness, Challenged Athletes Foundation, and Armed Forces YMCA were among those who were targeted.

Civilian organizations to volunteer. The San Diego Adaptive Sports Foundation was a local organization with a dedicated branch specific to wounded warriors. They built programs to engage wounded warriors in athletic events. The investigator provided first aid and other medical support to ensure a safe event with wounded warriors. Participation with events specific to wounded warriors allowed for discussion of the study intent. At these events, it was revealed that wounded warriors were not permitted to talk to anybody without explicit permission from their commander or case manager. Thus, no participants were obtained from this approach.

The investigator attended workshops and conferences, volunteered, and participated in 5K walks for the National Association of Mental Illness (NAMI) in an attempt to learn more about efforts to address PTSD as a specific focus of this study. At these events, there was no interaction or discussion of the study and no enrollees were recruited.

The Challenged Athletes Foundation (CAF), another civilian organization based in San Diego, CA and originally focused on disabled children, was building programs for wounded warriors. CAF assisted with organizing a surf program in Del Mar, CA with the Armed Forces YMCA from Naval Medical Center, San Diego for wounded warriors to include amputees, traumatic brain injuries, orthopedic injuries, PTSD, and cardiovascular injuries. The investigator attended the surf program as medical support on Thursdays in an effort to discuss the study and encourage enrollment. Though more than 10 individual discussions were conducted, none of the prospects who met inclusion criteria elected to participate.

The approach to join and volunteer with civilian wounded warrior organizations also allowed for dissemination of study information. The programs from these organizations were designed specifically for OEF/OIF. These efforts resulted in no enrollees after 10 months of volunteering.

Civilian organizations to promote research. Travel on the west coast to investigate opportunities to recruit participants included the VA system. Four VA hospitals were approached about enrollment in the study: VA of Palo Alto, CA; VA of Long Beach, CA; VA of Las Vegas, NV; and VA of San Diego, CA. Prosthetics-orthotics units were the departments having the most contact with amputees. In each of

the VAs, the investigator met with the PACT coordinator, Prosthetics/Orthotics supervisor, Vietnam Veterans Administration office manager, and the OEF/OIF Outreach Department. All were enthusiastic and agreed to post flyers to reach the population needed for enrollment. With this effort, two participants completed the consent and data collection instruments.

The Amputee Coalition of America, an organization that encourages research specific to amputees, had a structured method for investigators to promote research participation. An application was submitted with all requested documents and fee, similar to an Institutional Review Board approval. The grants coordinator approved the application on September 4, 2009 (Appendix E). The letter of approval, posting of the research study, and a letter of encouragement from Amputee Coalition of America for amputees who meet the criteria was to be disseminated among its members. In addition, permission was granted to reproduce and distribute the letter of approval, post the information on other websites, institutions, facilities, amputee support group meetings, offices, and organizations that service wounded warriors or challenged athletes.

Prosthetics. A recommendation was made to contact all prosthetist-orthotists in the San Diego area and apprise them of the study, requesting their assistance with enrollment. Eight separate companies serve the amputees in San Diego County, each personally visited with a packet of information, flyers for posting, and points of contact. Wounded warriors in San Diego had the option of civilian follow-up with their prosthetics; the VA estimated that 75% of those were seen in the community. When this was investigated, the actual amount was only 10%, lessening the exposure of the study to

qualified participants. All of these offices were visited and all agreed to post flyers but no participant enrollment ensued.

Military organizations to volunteer. The Armed Forces YMCA, developed under the umbrella of the national YMCA, is specific to military wounded warriors. Offices are located in the each military hospitals designated as a *Center of Excellence for Traumatic Limb Loss Care*. National Naval Medical Center Bethesda, MD; Walter Reed Army Medical Center, Washington, DC; Brooke Army Medical Center, San Antonio, TX; and Naval Medical Center, San Diego, CA are all centers specializing in traumatic limb loss. One benefit of having the Armed Forces YMCA in San Diego, CA is access to the U.S. Olympic Training Center in Chula Vista, CA. Many wounded warriors, especially those with limb loss, compete for the Paralympics games and train at the U.S. Olympic Training Center. Others who train for wounded warrior games within the military ranks also train at Olympic Training Centers with Olympic coaches volunteering their time to wounded warriors. The investigator volunteered to provide medical support at each of the Olympic-coached training sessions in San Diego, CA, without successfully enrolling any study subjects.

The approach of joining and volunteering at local civilian and military organizations offered promise, as many of the individuals engaged in the events met the inclusion criteria for this study. The investigator volunteered over 300 hours at nine different military and civilian organizations (i.e., Armed Services YMCA, Challenge Athletes Foundation , Wounded Warrior Project, San Diego Adaptive Sports Foundations, Disabled American Veterans, Veterans of Foreign Wars, National Association of Mental Illness, Wounded Warrior Project, the Veterans Village of San

Diego) as medical support in an effort to encourage study participation. Numerous participants met the inclusion criteria as having a traumatic limb loss due to military activity; however, these events focused on healing and potential subjects choose not to discuss the study in depth or enroll.

Military organization to promote research. Another IRB request for approval was submitted to the Naval Medical Center, San Diego, CA. An expedited approval granted in less than 2 weeks (Appendix F). This allowed the investigator to post the flyer for enrollment into the study. The quick approval and encouragement from the Naval Hospital personnel was promising; they felt the study would be of great value and their staff would support enrollment.

Three IRBs approved this study: University of San Diego, Amputee Coalition of America, and Naval Medical Center, San Diego. Despite extensive marketing, only one participant was recruited from these efforts, totaling three subjects.

Military Organization Interface

Centers of Excellence. After 7 months of recruiting efforts on the West Coast, the search for study participants was widened to the East Coast. Washington, DC houses two of the four Centers of Excellence in Traumatic Limb Loss as well as the National Wounded Warrior Program, the Army's version of the wounded warrior program, AW2 Warrior Transition Unit Headquarters, and many organizations for the caregivers of wounded warriors.

Travel to Jacksonville, FL, allowed for a personal interview with a wounded warrior magazine's editor. Additional travel yielded interviews with staff at National

Naval Medical Center, Bethesda, MD, Walter Reed Army Medical Center, Washington DC, and coordinators of the Army Wounded Warrior (AW2) program, Alexandria, VA.

Appointments with two individuals at the National Naval Medical Center, Bethesda, MD, and one at Walter Reed Army Medical Center involved days of learning and sharing. The division officer of the Complex Wound and Limb Salvage Center spent a full day escorting the investigator through several departments, sharing the progress of amputees once injured. Additionally, meetings were held with the trauma program coordinator, wound care center director, amputee rehabilitation program therapist, chief of nursing research, and the case manager monitoring all amputees whom had graduated from this amputee rehabilitation program, estimated to be 700 amputees. A thorough discussion of the study intentions, inclusion and exclusion criteria, recruitment efforts, and need to disseminate information to graduates ensued with each department. Upon returning to San Diego, the investigator received an e-mail stating that the center was not authorized to contact the wounded warriors with the study information and apologized for the inconvenience.

Another avenue was to contact staff at the Naval Medical Center, San Diego, CA, to discuss this study. After several attempts, a point of contact was located with access the willingness to escort the investigator to the departments serving the wounded warriors. Arrangements were made to meet with the chair of the Department of the American Legion of California, Heroes to Hometowns, who championed the study discussion at the Naval Medical Center, San Diego. Heroes to Hometowns is affiliated with the VFW, VVA, Armed Services YMCA, and the 82nd Airborne Association. The chair was gracious, enthusiastic, and optimistic that this research was possible, necessary,

and could be completed in San Diego, CA. The Naval Medical Center, San Diego Institutional Review Board approved delivery of study information packets including flyers, consent forms, instruments, and a point of contact. These packets were delivered to the Army and Marine Wounded Warrior Transition Units that case manage every wounded warrior located at the Naval Medical Center, San Diego.

At the Naval Medical Center, San Diego, the investigator met with the resource analyst for the Wounded Warrior Transition Unit. The discussion focused on the research study and requested assistance with the search for participants. Other meetings were conducted with the chief of the Comprehensive Combat Casualty Care Center, Director of the Armed Services YMCA, manager for the Federal Recovery Care Coordinator for those most severely injured, and the director of the Gait Analysis Laboratory and Prosthetics Department. Each of these meetings was met with enthusiasm and the implication was that it would not be difficult to find individuals meeting the criteria and willing to participate.

Another opportunity to present this study and encourage enrollment was at the community action meeting for wounded warriors. Representatives from the Army and Marine Warrior Transition Units, case managers, medical and non-medical care coordinators, and chaplains were in this session. Everyone in attendance was enthusiastic and supportive but no participants were enrolled with this dissemination of information.

Another visit to the Naval Medical Center, San Diego, CA, focused on the offices of the Health and Wellness Department where medical support is offered specific to wounded warriors, most with limb loss and PTSD. This department supports retired

wounded warriors who participate in national military warrior games and U.S. Paralympics events.

In summary, three of the four major centers of excellence for amputee care and rehabilitation were visited (i.e., Walter Reed Army Medical; National Naval Medical Center, Bethesda, MD; Naval Medical Center, San Diego, CA). With this approach, one participant agreed to complete the required documents for study enrollment.

United States Army Reserves. As an active army reservist, the researcher spent extensive time with medics and nurses in the military. Over the last 18 months, military personnel have been supportive of this study; often attempting to connect with someone who met the inclusion criteria. In the annual training settings, specifically at Naval Medical Center, San Diego, students and faculty of the medic courses would approach the amputee passersby and deliver a flyer or discuss the opportunity to be a participant in a study. Students who were enrolled in Combat Medic Advanced Skills Training course advised the investigator to go seek wounded warriors online, as most were communicating on the computer. Graduates of the Combat Medic Advanced Skills Training course posted information about the study on a Facebook website they developed as well as on the Amputee Coalition of America website.

Another idea was to contact those known through the media with traumatic limb loss to solicit their interest, participation, and assist with encouraging others to participate. This attempt failed after much effort, financial investment, and initiative. Others in the military with rank, positions of authority, and connections worldwide assisted with spreading the word to organizations, support group leaders, researchers, unit members, and politicians. Many who were contacted were encouraging and assisted with

dissemination of information, forwarding documents to specific personnel who oversaw wounded warriors, but no enrollee response ensued.

Over the 18 months of searching for study participants, the investigator conducted a minimum of 22 meetings with over 150 hours of time to share information with individuals and groups about the study specifics and need for enrollment. The investigator believed that, with the affiliation as an active army reservist, study enrollment would be possible.

Wounded warrior interface. The Wounded Warrior Project (WWP), based in Washington, DC, is a national organization designed to help all wounded warriors from OEF and OIF. The organization encourages participation in many types of athletic and artistic events for wounded warriors and their families. One Southern California bike ride was a 3-day event that the wounded warriors and support personnel participated, including medical, bike mechanics, security, media, photographers, and mess hall (meals). Three 1-day rides included the cities of Santa Barbara, Santa Monica, and San Diego, CA. Similar events were designed throughout the United States to bring awareness of soldier issues and raise funds. In 2009, the investigator negotiated with the director of the WWP to ride with the wounded warriors as medical support for the 3-day event, something not typically open to the community unless there is a need and the individual has proven security clearances. In the 2009 ride, 23 wounded warriors participated, including six amputees with 15 support personnel. Two of the six amputees on the ride agreed to participate in the study, but never completed the required documents to be enrolled, despite repeated electronic and phone contact.

After contacting the editor of the *After Action Report*, the magazine of the wounded warrior project, a visit was made to Jacksonville, FL, to meet with her and discuss the study efforts. This publication featured only military wounded with traumatic brain injury, burns, amputations, and PTSD. She was supportive of the study, searched for those who met the inclusion criteria, and request that they participate. The discussion was encouraging, with a plan to post the flyer in the *After Action Report*. Unfortunately, no study participants were recruited using this approach.

Community based warrior transition units. The Army Wounded Warrior Program (AW2) headquarters, located in Alexandria, VA is where case managers supervise the care of the wounded warriors throughout the United States. One suggestion from a military colleague was to meet with the supervisor of all of the case managers to obtain permission in disseminating study information to those who met the inclusion criteria. Throughout a 4-hour discussion with several key leaders, their response was enthusiastic, suggestions were given as well as ideas to encourage enrollment. Their eagerness suggested a favorable outcome from among their caseload. A memorandum was to be disseminated to all the case managers with request for participation of those who met the criteria. Unfortunately, follow-up correspondence stated that authorization to inform the wounded warriors of the study was denied.

When the study was expanded to include amputees from any war or military training accident, an effort was made to update all parties previously contacted, including the six California Advocates offices for the AW2 Program with information about the modified IRB and continued need for study participants. The approach did not result in any participants.

Marketing

Publications. One route to disseminate study information was to publish in a local magazine and a national wound care journal. The *University of San Diego Magazine* editor contacted the investigator and requested a short article on the study topic be submitted. The article featured the role as an army nurse and doctoral student and the impact on wounded warriors with limb loss. The column led to awareness of community members, requests about the study population, and questions about what could be done to encourage enrollment. The feature led to a luncheon with a retired dean who had a special interest in wounded warrior issues. She was interested in the study topic and continues to be an inspiration for doctoral completion, but there were no participants or points of contact for study enrollment.

Another article was written in the *Ostomy Wound Journal* with the intention of disseminating information about the study and encouraging enrollment. The result was a 4-page article that drew attention to the WOCN Wound Care Forum. This journal is distributed to more than 7,000 clinicians in the United States and 1,000 clinicians worldwide.

Four publications were contacted with a distribution over 10,000 subscribers, including submissions to the *University of San Diego Magazine*, *National Association of Mental Illness Newsletter*, *Ostomy Wound Management International Journal*, and the *Amputee Coalition of America Magazine*. The publications created discussion on forums and electronically, but did not lead to any study participation.

Websites. Opportunities to disseminate information about this particular study and encourage participation went to research organizations, institutions, and facilities,

requesting contact with their websites by allowing the posting of a flyer. The Amputee Coalition of America posted the flyer and linked the study to other websites designed for amputees, promoting study enrollment electronically to its members. Unfortunately, only one inquiry resulted from this method. The Dallas Amputee Network Support Group discovered the study enrollment opportunity and contacted the investigator offering to participate in the study after the study enrollment had ended.

Flyers and forums. The study was also posted on other wound care websites allowing wound care, foot care, professional practice nurses, physicians, or physical therapists visiting the site to become aware of the case study and encourage enrollment. With access to the Army Knowledge Online (an official online military forum), the research was posted on a multitude of research sites and soldier forums with no response.

Other opportunity to post the flyer and disseminate information was via the Society of Wound Ostomy Continence Nurses' Professional Practice Forum and Wound Care Forums. These forums comprise trauma and wound colleagues worldwide who communicate through electronic channels to search for potential participants. This mechanism was pursued because the three instruments could be completed independently by phone, Skype, or electronically. The investigator also offered to travel to locations if the amputee preferred an interview in person. There was no response or study enrollment with this offer.

All of the California and national offices for the Veterans of Foreign Wars, Vietnam Veterans Association, and Disabled American Veterans offices were contacted electronically and by phone. Messages were left with information about the study and flyers sent electronically, to no avail. The Veterans Village of San Diego (VVSD) was

visited monthly with the investigator inquiring about amputees that may have been newly admitted to the program. One prospect had an arm amputated and was approached; however, the accident was not military related.

At one Pacific coast meeting of the Wound Ostomy Continence Nurses' Society in Northern California, a suggestion was made to visit the local community colleges, specifically the veterans' affairs and military recruitment offices on the campus as many disabled veterans were enrolled in college. Community colleges in Southern and Northern California were visited in person, meeting with office personnel, posting flyers, and leaving packets. Requests for an electronic version of the flyer, consent, and instruments were forwarded to those who could distribute materials to others meeting inclusion criteria. There was no response or study enrollment with this mechanism.

Other organizations contacted included the Amputees in Motion International and Stu Siegel Productions, which trains veterans in film making. Eighteen forums with four different sites and over 1,000 hits each resulted in no study enrollment.

Support groups. After expansion of the study, an effort to reach older veterans with an amputation was conducted (see Appendix G). The investigator offered to speak to amputee support groups to explain the feasibility study and request enrollment. The only amputee support group that contacted the investigator was the Dallas Amputee Network, who discovered the opportunity through the Amputee Coalition of America website. Multiple attempts were made to contact leaders of amputee support groups at each of the VAs and the Center's of Excellence for Amputee Care and Rehabilitation to no avail.

Conclusion of Efforts to Enroll Study Participants

The data gathering process was comprehensive and exhaustive. Every effort was acted on to follow leads and create opportunities to enroll study participants. After 8 months of recruiting for participants with OEF/OIF who have sustained limb loss in the theater of combat, it was evident that few from this group were going to participate. The study was then opened to any personnel with military-related limb loss. This would include individuals with amputations sustained during military training, war, or military motor vehicle accidents. Such expansion created opportunities to involve organizations previously not considered, including VVA, VFW, DAV, VVSD, and amputee support groups with older amputees. Only one study participant agreed to participate from a previous military-related accident that resulted in an amputation.

Notification to the Wound Ostomy Continence Nurses' Society Wound and Professional Practice Forums was sent regarding the expansion of the study, continued need for participants, and requested suggestions for recruitment. Over the 18-month search for study participants, 300-plus wounded warriors were approached about their participation in this study. When study enrollment ended, only three individuals had consented and completed the required documents for participation in this study.

Analysis of Feasibility

With the failure to enroll a sufficient number of participants, the decision was made to explore the factors limiting the feasibility of this study. The work of Yin (2009) was used to examine the rival explanations of the insights into human and social processes limiting the research design chosen.

After analysis of a chronological account of events and a description of all of the approaches attempted, including the time expended, number of personnel involved, and miles traveled, it was apparent that the researcher, while qualified and situated to conduct this study, had done everything legally, ethically, and morally possible to encourage participation. The possible explanations of behaviors witnessed include chain of command, fear of retribution, feelings of being overwhelmed, apathy, signs and symptoms of phantom limb pain, depression, other mental illnesses, fear of discharge, or other repercussions within the military ranks or impairing medical assistance. After 18 months of soliciting enrollment with more than 12 different approaches, this researcher recognized the improbability of enrolling a sufficient number of military personnel to complete the study.

Rival Explanations

To describe the poor response for study enrollment, rival explanations are used based on a case study research (Yin, 2009). Rival explanations are a general analytic strategy to define and test alternative explanations. The typical hypothesis in an evaluation is that the observed outcomes were a result of some other influence. The goal is to focus on and attempt to collect evidence about the possible *other influences* resulting in the stated outcome. In this analysis, few military personnel choose to participate in this correlational study investigating quality of well-being and PTSD after traumatic limb loss.

Direct rival is defined as the *real reason* for the result or outcome. *Real-life rivals* are ones that need to be carefully identified during data collection and may not be apparent until one is in the midst or at the end of data collection. In this study, only three

military personnel who met inclusion criteria chose to participate in this study. Rival theory suggests that study enrollment failed because of forces often beyond control of the individuals involved in the research (Yin, 2009).

There are five rival explanations determined from this case study report and many other influences that assisted in understanding the study's outcome. Those explanations fall into three categories: implementation rival, super rival, and societal rival.

Implementation rival asks the question, *Was it done right?* Super rival is a force larger than the intervention opportunity. Societal rival recognizes that there are social trends rather than particular forces or interventions that account for the results (Yin, 2009)

Implementation rival is a constant threat in data collection. The most important implementation rival for this study was specific to the study design. The intended study population, being wounded, affiliated with the military, and an amputee, is a visible, vulnerable, and high profile group. The approach to the wounded warrior was difficult, even with permission and access granted. Every effort was made to respect the wounded warriors' privacy while discussing the opportunity to participate in a study investigating function and PTSD. Occasionally, prospective subjects asked, "What is in it for me?" These individuals were busy with appointments, meetings, and events. The devastating outcome of one, two, or three lost limbs consumed them and their families physically and emotionally. Military personnel are often times fearful of being labeled as mentally ill. PTSD consumes the wounded warrior with feelings of being overwhelmed and emotionally distant. Fear of income loss or gainful employment, particularly in a depressed economy, is a factor to consider in requesting one risk being labeled or

diagnosed with a mental illness. Though the tools were concise, it may have been too much time and effort to focus at this pivotal time.

Super rival is a force larger than the any single one component (Yin, 2009). Political forces, military procedure, military medicine, and disability are all super forces. Fear of retribution exists in the military ranks. The military leadership at every level has an obligation to protect subordinates. Safety while conducting the primary mission is a military goal. The military as a whole and military medicine have political implications at every echelon and level of care. With negative historical events (e.g., disapproving public opinion after Vietnam War and Desert Storm), comparisons have been used in the media during OEF/OIF. Media accounts in February 2007, at the same time that this study was being designed, detailed negative soldier and family care at Walter Reed Army Medical Center, Washington, DC. Headlines described neglect as the national leaders, including the Pentagon, Congress, and the White House, demanded answers. Wounded warriors with continuing physical and mental issues were being housed after discharge in substandard conditions. Injured military personnel were awaiting further treatment or discharge versus active duty decisions.

As the result of unfavorable findings, the Army redefined its wounded warrior care program and commitment, creating a system that puts soldiers and family members at the center of care and surrounded by protective layers of leadership, case managers, doctors, support specialists, and senior leader oversight (Baker, 2008). Since that time, all military efforts have been scrutinized.

Military mental health and suicide rates are currently being tracked and published with great concern by military medicine, commanders, and mental health workers. From

2002 - 2008, nearly 50,000 veterans from the Iraq and Afghanistan wars have been diagnosed with PTSD, but fewer than 10% of those have completed the recommended treatment regimen (Dottinga, 2010). Males, veterans under the age of 25, those who live in rural areas, and those who received their diagnoses in primary-care clinics, therefore necessitating referrals to mental health programs, often do not receive timely intervention. Increasing mental health issues are being seen for the first time in the U.S. Army Reserves as the rate of suicide in reservists has surpassed those in active duty.

The civilian nurse researcher collecting data for a correlational study about PTSD in the military may pose a potential threat to commanders protecting their subordinates. The effect of PTSD is a significant super rival. The literature has demonstrated the affect of PTSD after injury as a major influence on the outcome of physical and psychological health of the wounded warrior. As such, an individual usually avoids conversation about the physical injury. Asking amputation-related questions and collecting data about physical symptoms to ascertain function and PTSD response were not feasible.

Society rival is related to social trends; not any particular force or intervention can account for the results (Yin, 2009). Anecdotal indications are that wounded warriors are constantly being asked to participate in research studies, as the war effort and outcomes have renewed focus. Never before have so many military personnel sustain such devastating injuries and survive. The wounded warrior with limb loss has a minimum of 1-2 years of structured physical, emotional, and psychological rehabilitation. Current interventions (e.g., prosthetics fittings, gait analysis, training), and use of other assistive devices are being developed as more military personnel return with traumatic injuries. Other trends relate to the type of injuries, age of those injured, and caregiver issues.

More young, once able-bodied amputees now need the help of their older parents – the 60 to 70 year old mothers and fathers (Yeoman, 2008) – or young wives with small children. The typical wounded warrior with limb loss in this war is a 26-year-old unmarried male. The social support that extends to the healthcare system and the military are usually limited to the immediate family.

Other Influences

Other influences include feelings of being overwhelmed or the need for a sense of control over *not* participating in a study, as they were not *ordered or expected* to participate. These wounded warriors often feel little control over their lives and non-committal is a method of control. In one opportunity while marketing study participation, the military member stated that he is required to get permission to discuss his case with anybody. At that same event, the comment was made that, unless he was ordered to participate, he preferred to not participate.

An informal survey was conducted just prior to the decision to cease study enrollment (see Appendix H). Online on the Wound Ostomy Continence Professional Practice and Wound Care Forum, the survey asked why military personnel would not participate in the study as designed. This was an effort to enlist colleagues to identify potential participants now 18 months after the initial call out on the forum. The attempt was futile with no leads for study participation.

Summary of Rival Explanations

By building the rival explanations to examine the outcomes of this study analysis, analytical technique was used to redefine a set of ideas that support the case that at this time; the data intended to be collected was not feasible. The original purpose of the study

was to investigate the relationship between quality of well-being (function) and impact of event (PTSD) after a traumatic limb loss in combat or in a military training accident.

This study population is protected for many reasons. Defined protected populations include those in the military, disabled, or with a mental illness. The wounded warrior is disabled, possibly mentally ill (e.g., PTSD, depression), and affiliated with the military. After amputation, feelings of an altered body image, avoidance, depression, and social isolation are common (Behel, 2002). This reveals an understanding of the non-committal participating in a research study. Becker (1997) wrote that disruption was expressed as voices and feelings that were muted and unarticulated. Military personnel are expected to *tough it out* emotionally and physically with great value placed on stoicism in the management of injury, illness, pain, and mental illness. This study population was not able to participate due to a cultural response to chaos.

Many factors influence adjustment to an amputation. These individuals often struggle with disability as a lifelong adjustment, especially when sudden and traumatic, with numerous post physical and mental health complications (Melcer et al., 2010). The deformity of amputation often evokes discrimination, shame, and feelings of vulnerability to victimization. The role of values, meaning, and perspective is important for positive adjustment considering social activity, physical activity, mobility, control of phantom limb syndrome, and depression. These were all possible rivals to study enrollment at this time.

The investigator traveled to Dallas and offered a 1-hour block of instruction on the wounds of war and doctoral study status for the Dallas Amputee Network. Even though the search for study participants had ended, the intent was to request some insight

as to why this study was not feasible. The response from the audience was positive. An informal written survey was conducted after this presentation of the audience and summarized for discussion (Appendix I).

Evaluation and Summary of Rival Explanations

Rival explanations as patterns with real-life events resulted in few warriors with traumatic limb loss who volunteered to participate in this study. Those that did participate were supportive of the study efforts and tried to encourage their comrades who met inclusion criteria. After the study enrollment ceased, a notification went out to those who did participate to let them know of the final outcome. One of the participants took the time to call and apologize for his comrades and express how important this study would be in the future.

In retrospect, many opportunities, both planned and unplanned, were leveraged with little participant response. Opportunities were abundant for knowledge gained by the enthusiasm from health care providers, other researchers, community personnel, and the wounded themselves and their families. Every encounter directly and indirectly led the researcher to believe the study was timely, important, and possible. Communication electronically, in writing, in person, and via telephone were persevered. Efforts to enroll participants were pursued vigorously as demonstrated by the numerical account of approaches, opportunities with both military and civilian, hours volunteered, articles written, flyers disseminated, miles traveled, and participation on forums.

The following summarizes the attempts and efforts in relation to rival explanations:

- # of forum discussions with convenience sample response – over 18 forum discussions on four different sites with greater than 1000 hits each
- # of meetings specific to doctoral study presentations – 22 with 150 hours of time
- # of other presentations where doctoral work discussed – 69
- # in attendance at conferences – over 1,300
- # of Centers of Excellence for Amputee Care – 3 with more than 50 hours on the ground
- # of organizational activities – 9 different organizations affiliated with greater than 300 volunteer hours
- # of air miles – more than 31,000
- # of ground miles – over 5,000
- # of publications with distribution range – 3 publications with over 10,000 in distribution
- # of IRBs approved – 3
- # of wounded approached – over 300
- # actually enrolled – 2 prior to expansion, 1 after IRB expansion (see Diagram of Study Efforts, Appendix J)

The efforts to engage interest in study participation were multi-dimensional, spanning personal interviews, multiple IRBs, amputee support groups, clinical supports for amputees, and with military and civilian key staff. The efforts included contacting prosthetic and physician organizations, political and national nursing groups and forums, and use of Internet technology. These efforts spanned over 18 months and involved cross-country travel on several occasions.

Rival explanations must be used for the lack of enrollment into a study involving wounded warriors, specifically those with traumatic limb loss. Melcer et al. (2010) supported the conclusion and recommended retrospective record review rather than interviews. A recent review of the literature on combat injuries revealed 11 studies published from 2007-2010. Of those 11; five were retrospective analysis using military databases and two used the Navy-Marine Corp Combat Trauma Registry Expeditionary Medical Encounter Database (Navy-MC CTR EMED) or Joint Theater Trauma Registry. Melcer et al (2010) used three separate databases to include CHAMPUS, which comes from Department of Defense Tricare Management Activity, Defense Manpower Data Center, and the Defense Enrollment Eligibility Reporting System; Amputee Care Program Database; and the Navy-Marine Corp CTR EMED. With Melcer's (2010) article, it became obvious to the investigator that the proposed study could not be accomplished as designed. A future study with a major military healthcare system and research team with access to databases would be able to explore certain questions based on years of data collection.

Implications for Future Research

Gathering data specific to the quality of well-being and comparing that with levels of PTSD has the potential to advance scholarly work in the nursing areas of rehabilitation, psychiatric, and wound healing. Gathering data on demographics (e.g., personal, environment, disability factors) may isolate specific indicators for future programs, briefings, and insights into how pre and post intervention may be conducted prior to and after deployments.

The development and validation of *best practice* guidelines for multidisciplinary care of the amputee are essential. In the context of current results and increasing levels of expectations for function following amputation, the development of more sensitive and militarily appropriate outcome monitors is necessary. Future studies designed such as this study may be one of many studies to facilitate that best practice guidelines are implemented and followed to allow for the greatest function and better quality of life after traumatic amputation by recognizing those with symptoms of PTSD and other personal, environmental, and disability indicators that may support a positive outcome.

From reviewing three responses, this researcher is further convinced that the study as originally designed will be valuable in the future, for health care providers, families, and those involved in programs and policy development for wounded warriors. The results of a larger study may be used for both military and civilian sectors to improve care and provide intervention in a timely manner to reduce complications, both physical and mental. From reviewing the evidence of risk of PTSD after traumatic limb loss, more attention is warranted from researchers studying the adjustment to disability process. More studies need to explore factors that contribute to optimal adjustment after any traumatic event leading to physical injury. Future studies should also incorporate short term and long-term adjustment and consider mixed methods to include a qualitative piece with quantitative exploration.

Conclusion

From the above discussion of rival explanations, it can be posited that

1. This study design involving personal interviews was premature and ahead of its time.

2. At the current time, a large-scale retrospective data analysis is a more feasible means of approach.

The wounded warrior issues are current, real-life events, not historical. This study topic and need for participants is a political, ethical, economic, and medical issue. In the future, this study as designed may be of great benefit. Currently, the questions are too fresh for the wounded from this war to consider addressing. Right now, they are trying to get their lives in order after chaos. The information will be of value for both the military and civilian sectors especially when addressing physical and mental illness signs and symptoms.

When the economy is more stable, the unemployment rate reduced, when the war ends and the U.S. military is returned to their own soil, an investigation such as this may be feasible. With this knowledge, trauma centers and military medicine may restructure their programs with specific intentions to address symptoms and treat mental (mind), physical (body), and spiritual (spirit) issues. Focusing on the wounded warrior from OEF/OIF is also an opportunity to study stump management, wound care, burn care, and rehabilitation. With a better understanding of signs and symptoms such as phantom limb syndrome, new rarely seen post-amputation complications such as heterotropic ossification, pain after limb loss, and PTSD that leads to depression, suicide, and social isolation appropriate and timely intervention may be developed.

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Appendix A

Demographic Data Questionnaire

Physical Factors of Soldier

Age: _____ Code _____

Gender: Male: _____ Female: _____

Race/Ethnicity: White ___ Latino ___ Black ___ Asian ___ Unknown ___

American Indian ___ Hawaiian ___

Rank/Rate: _____ Branch of Service: _____

Service Type: _____ Years Served: _____ Date of Injury:
_____**Disability Factors – Amputations**

Number of Amputations: _____

Location of Amputations:

Toes: _____ # _____ Fingers: _____ # _____ Foot: _____ L or R Hand: _____ L or R

Below the Knee: ___ Above the Knee: ___ Below the Elbow: ___ Above the Elbow:
_____**Environmental Factors**Physical Living Quarters:
_____Current Living Situation:
_____Study/Work Environment:
_____**What would your ideal situation be?**

_____**Any COMMENTS:**

Appendix B

Flyer for Recruiting Participants

Please consider taking part in a research study that looks at quality of well-being and impact of events following traumatic limb loss sustained during any military training activity or in combat.

If you:

- Have sustained one or more upper or lower limb traumatic amputation/s in combat or any military training activity;
- And it's been at least a year since your injury...

You are invited to be in a research study.

- Your participation will include filling out three questionnaires that takes about 45 minutes.
- You will also be asked for permission to take your picture, but you do NOT have to if you choose not to.

A graduate nursing student researcher from the University of San Diego is looking for participants for this dissertation research study.

If you are interested and want to discuss or participate in this study;

Please contact
Shelly R. Burdette-Taylor RN
PhD Doctoral Candidate
858-663-4150 mobile
Shelly@taylordhealth.com
www.taylordhealth.com

Appendix D

Informed Consent

Research Participant Consent Form

Relationship between Quality of Well-Being and Impact of the Event among Military Personnel that resulted in a Traumatic Amputation during any Military Training Activity or in Combat

Introduction

Shelly Burdette-Taylor is a doctoral student in nursing at the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a dissertation study she is conducting for the purpose of exploring how well soldiers who have lost one or more limbs are doing with quality of well-being and impact of the event.

Procedures

The research project will involve one meeting/or may be completed electronically that will take about 20-30 minutes. Shelly will ask you to fill out 3 questionnaires that will ask you information about how you are feeling emotionally right now and what your quality of well-being is like. A typical question on these questionnaires is, "Are you able to be physically active in your present life?" You will also be asked general questions about yourself such as age, occupation, and the kind of environment and support you have. After you finish filling out the forms, you have the option for Shelly to take your picture. You do not have to have your picture taken. If you do choose to have it taken, Shelly will give you another form called the Media Release Form to sign and a copy to

keep. Shelly will use your picture to analyze your level of well-being. She may show your picture at professional meetings for nurses, physicians, and other health care professionals, but not anywhere else, and will never use your name with the picture. She will not use your photograph for commercial or profit purposes, and she will not put it on the Internet. Be sure to check the box at the end of this form indicating whether it's OK for Shelly to take a picture or not.

Risks

There may be a risk that you may feel strong emotions like anxiety or sadness while filling out the questionnaires. You can stop at any time to rest, decide not to fill out all the forms, or withdraw from the study anytime.

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call **San Diego Mental Health Hotline at 1-800-479-3339** (toll-free 24 hours a day). You may also call the Veterans Administration: **Veteran Counseling and Guidance Center at (619) 294-2040**.

Benefits

The benefit to participating will be in knowing that you helped nurses, physicians, other healthcare providers, and the general public know more about how to help people who have experienced traumatic injury in combat or in military training and how to reach a greater level of function by being more proactive and identifying needs in a timely manner.

Participant Costs

The only cost to you is 45 minutes of your time.

Confidentiality

Any information provided and/or identifying records will remain confidential and safeguarded in a locked file in Shelly Burdette-Taylor's home for a minimum of five years. All data collected from you will be coded with a number and not your name. The results of the research project may be made public and presented in professional journals or meetings, but results will only be reported as a group, and not individually. If you do agree to have your picture taken, it will be shown only at professional meetings for nurses, physicians, and other health care professionals. Your name will never be used with your picture, only a code number.

Voluntary Participation and Withdrawal

Participation in the research project is entirely voluntary and you can refuse to answer any question and/or quit at any time. Should you choose to quit, no one will be upset with you. Deciding not to participate or answer some of the questions will have no effect on your health care or any other services you might receive from doctors, nurses, or social services, or your status in the U.S. armed services.

More Information

If you have any additional questions about this research project, please contact Michele (Shelly) R. Burdette-Taylor (858) 663-4150 or shelly@taylordhealth.com. You may also contact Dr. Jane Georges, the professor who is supervising Shelly's research, at the University of San Diego School of Nursing (619) 260-4566 or at jgeorges@sandiego.edu for additional information.

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Please check one space below and sign:

YES, it's OK for Shelly to take my picture. I have also signed and received a copy of the Media Release Form.

NO THANKS- I do not wish for Shelly to take my picture, but I will fill out the forms.

Signature of Participant

Date

Name of Participant (Printed)

Signature of Investigator

Date

Appendix E

Amputee Coalition of America Research Review Board Approval



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Appendix F

Naval Medical Center, San Diego Institutional Review Board Approval

14 November 2009

MEMORANDUM FROM:

Michele (Shelly) R. Burdette-Taylor RN-BC, MSN, CWCN, CFCN, PhD
 LTC, AN, USAR, 9th BN, 4th BDE, 100th DIV, Camp Parks, Dublin, CA

FOR:

Chair of IRB, National Naval Medical Center, San Diego, California.

SUBJECT:

Request Approval to Post a Study Flyer for Recruitment.

I, Michele R. Burdette-Taylor, am a PhD candidate at the University of San Diego, Hahn School of Nursing completing a dissertation and trying to enroll prior, or present military who have sustained limb/s loss in combat or a military training exercise. The study I have proposed is a correlational design investigating the Quality of Well-Being (function) and Impact of Events (PTSD) after a traumatic limb loss in military activity.

I propose to interview 20-30 participants and complete three short questionnaires that should take 30-40 minutes. There are three paper instruments as described in attachments:

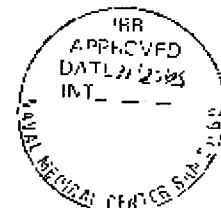
1. USD IRB approval and amendment
2. Flyer approved for recruitment with inclusion criteria
3. Abstract of the study

Your consideration of this request is greatly appreciated.

Points of contact (POC) are listed below for continued dialogue, questions, and/or suggestions to recruit participants that may meet inclusion criteria

Michele (Shelly) R. Burdette-Taylor RN-BC, MSN, CWCN, CFCN, PhD
 TayLORD Health LLC, CFO/Curriculum Designer
 858-663-4150 mobile
 858-872-8148 office/fax
shelly@taylordhealth.com
burdette_taylor_michele@us.army.mil

Cc: Angelita J.C. Altronte, CAPT, NC, USN, PhD, RN
 Head, Nursing Research and Analysis
 Naval Medical Center San Diego



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Appendix H

WOCN Wound Forum Informal Survey of Colleagues about Feasibility of Studying IES-R and QWB-SA with Military Personnel Conducted July 2010

Requested information on “why the troops would not/could not/did not participate” in this correlational study investigating the relationship between quality of well-being and impact of event after a traumatic limb loss?

Responses:

- Overexposure of this population to studies and attention
- Touchy feely types of questions make many/most people uncomfortable
- Fear of being labeled with a mental disorder, such as PTSD
- Maybe they haven’t finished working it through in their own head yet
- Maybe they are afraid that if they comment truthfully they may not get the proper care they need or deserve
- Oh brother – another person trying to crawl into my head
- If you out rank them they may not feel they can talk to you freely
- Maybe they are too busy processing things and working through rehab to have one more thing on their mind
- Maybe it is anger and your study represents another establishment – answering questions about such a personal thing must be hard especially with that age group
- Those in command do not like any negative press
- Think they are all suffering from PTSD – facing a questionnaire is one thing with depression that they cannot wrap their minds around
- They are overwhelmed by day to day life/adjustment and don’t really feel it will impact them so why bother
- Mostly political and economical – having young men and women losing limbs and life in combat that many of us do not understand is not something that the government probably wants to be studied or researched – how do we know that these heros are getting what they need when they need it regarding their care
- “Part of non talking is the stoic attitude the Army teaches and part of it is personality” – recorded from a wound care colleague whose husband loss a limb in Vietnam – even now 44 years later – he will not talk about injuries nor discuss what happened

Words of Encouragement:

- I thought when you first started this study you’d have so many people willing to participate, and you’d be turning others away! Go figure!
- Keep on writing
- I know you have worked very hard on this – hang in there
- Personally, I think it would be a very interesting to read and think you picked a great area to study
- Wanted to add that I feel that this would have been very valuable and am sorry that you did not get access

Appendix I

PhD Study Survey done at the Dallas Amputee Network
Monday August 9, 2010

Question was asked in writing –

Why do you think it was so difficult to get military personnel to participate in a study investigating the quality of well-being and impact of event after a traumatic limb loss?

Results from respondents and comments.

11 Male, 7 female participated

11 amputees, 7 non-amputees

11 family, 2 friends, 5 health care professionals

Average age 54, 6 prior military, 12 no prior military

Of possible influences on decision not to participate:

2 - Political, 9 - Overwhelmed, 3 - Do Not Care, 4 - Exhausted, 9 - Social Stigma,
8 - Fear of Retaliation, 4 - Chain of Command

Other Comments:

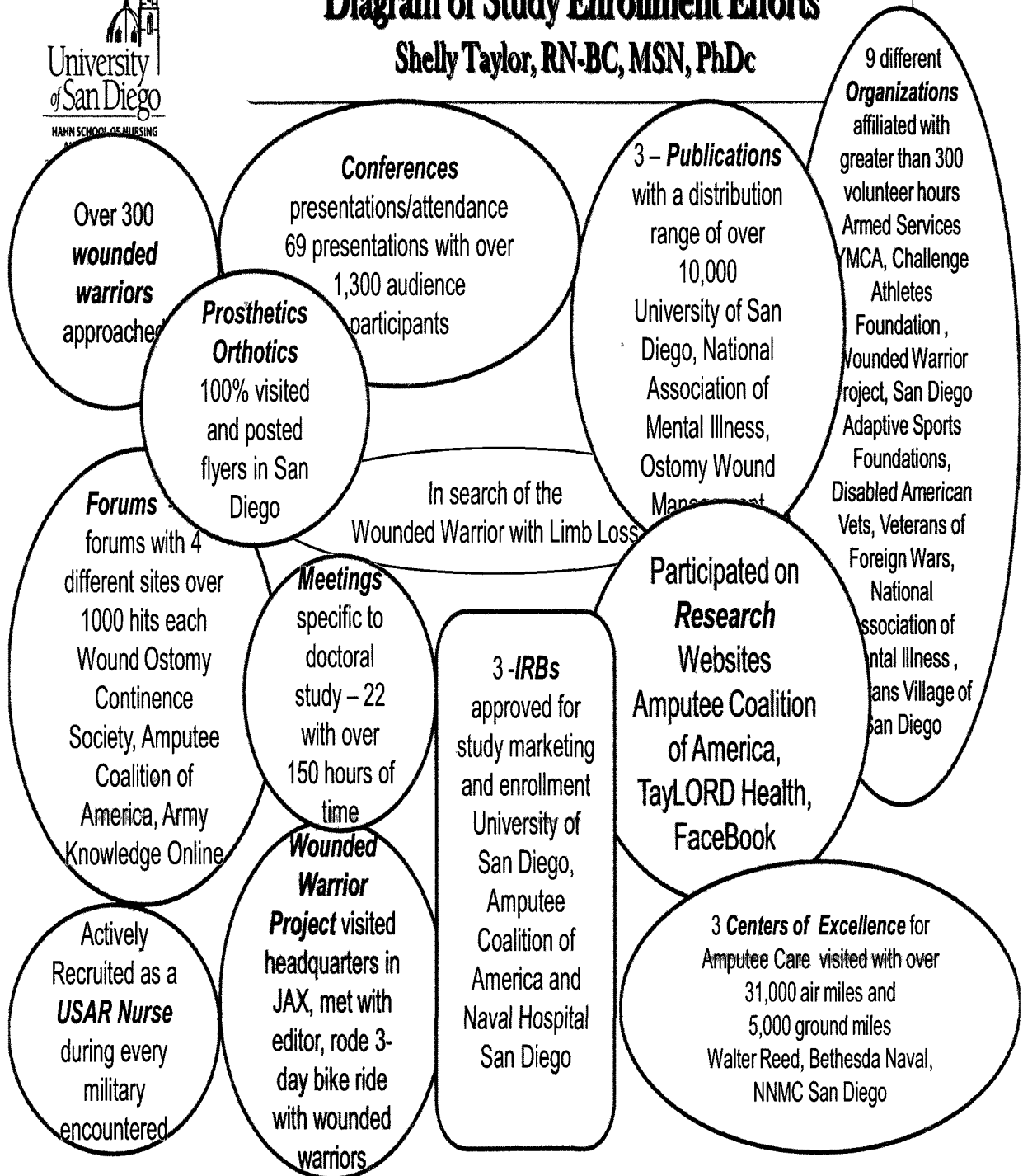
- To quick after the accident – must come to grips first
- Useless – it would not help them – frustrated with military care
- Proud and do not want to feel they are not strong
- We are military active duty and vets and our pride prevents us from asking or admitting we need help!!!!
- They may have had PTSD or were otherwise depressed, had too much to do or think about and could not handle an additional task
- US military is not a democracy – the price of freedom is very costly
- It is the unwritten contract of camaraderie and patriotism given as needed
- They may think it will not help and that nobody really cares
- Maybe they think that having to talk about it will bring up memories that they have tried not to think about
- Uncertain of ability to return to active service, uncertain of overall effect of future life, work, marriage
- Rumor hearsay there is still many problems with PTSD the fight to prove your case and although I am not in the military I read, listen, and talk about these problems. I think it is in the many more aspects of the wounded warriors than PTSD
- I do not understand why anyone would not want to participate in research that would impact future success in rehabilitation of our brave military and medical Americans

Appendix J



Diagram of Study Enrollment Efforts

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Appendix K

Summary of Quality of Well-Being Results

18 Function Limitations – Recorded - 3-4 each

- limb loss
- prosthesis
- hearing loss
- use of eye glasses or contacts
- skin deformity or burn

26 Symptoms - CPX – physical / mental symptoms or problems – 6-12 each

- headache
- dizziness or ear ache
- toothache or jaw pain
- chest pain or other discomfort in the chest
- nausea or other GI upset
- difficulty with BM, rectal area pain
- pain in neck or back
- pain in hips
- trouble falling asleep or staying asleep
- excessive worry
- feelings of frustration
- taking OTC meds
- feelings of no control over life events
- feeling of isolation or lonely

11 Dysfunction Descriptor and Scale Steps – score range results 11-15 (0-15)

Mobility – all recorded NOT limited as they were driving own vehicle all 5's

Physical Activity – 2 of 3 were recorded as 3 of 4 on scale as they were limited in walking limping using prosthesis, in wheelchair, or having difficulty bending over, not walking as fast as others

Social Activity – 1 of 3 recorded as 3 of 5 on scale as limited in major role activities – recorded limited in doing some of the usual activities or needed help, limited in visiting with family, doing hobbies, shopping, recreational or religious activities, all three points in time recorded had to change plans or activities because of health