# Executive Summary Amputee Veteran Project Phase II and Phase III

Report Prepared for the Amputee Veteran Research Project, an Initiative of the Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research

March 20, 2011



School of Liberal Arts Indiana University-Indianapolis

#### ACKNOWLEDGEMENTS

The authors acknowledge the Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research and its Co-Directors, Dr. Mark Sothmann and Dr. Stephen Wilson for their support in conducting this research under terms of Grant #W81XWH-09-1-0375, " Creating the Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research," from the U.S. Department of Defense. Use of the data, conclusions, and opinions expressed in this work are the sole responsibility of the authors and do not necessarily reflect the conclusions or opinions of the Indiana-Ohio Center or the Department of Defense.

We would also like to acknowledge the work of Professor Phil Scarpino and his graduate student research assistant, Janna Bennett, in the Department of History at Indiana University-Indianapolis. Dr. Scarpino and Ms. Bennett completed the interviews. Jim Wolf and the IUPUI School of Liberal Arts Survey Research Center were responsible for fielding the survey data collection and report preparation. Professor Carrie Foote and her graduate student research assistant, Regina Pessagno were responsible for analyzing the interview data and preparing reports that summarized the major findings from the interviews.

Other members of the research team also provided valuable input on various stages of the research. These include the two principal investigators, Professor David Bodenhamer (The Polis Center and Department of History, Indiana University-Indianapolis) and Professor Joyce MacKinnon (Department of Health and Rehabilitative Sciences, Indiana University-Indianapolis), along with Ms. Karen Comer (Project Coordinator, The Polis Center) and Professor Seth Messinger (Qualitative Consultant, University of Maryland Baltimore County). In addition, we acknowledge Chris Robbins (Department of Health and Rehabilitative Sciences, Indiana University-Indianapolis) and Denise Dearth (The Polis Center, Indiana University-Indianapolis), who were responsible for participant recruitment. Chris was also responsible for analyzing much of the survey data.

Two Vietnam veterans who sustained combat-related limb loss contributed their personal insights to the development of interview guides and other aspects of the project - Mike Buchanan, who serves on the project's advisory board, and Gary May, Professor of Social Work at the University of Southern Indiana. We would also like to thank Operation Iraqi Freedom Veteran, Chad McMahon (Outreach Coordinator), for his work on the project. Finally, a heartfelt thanks to the Vietnam veterans themselves for participating in this important project.

# TABLE OF CONTENTS

ACKNOWLEDGEMENTS	2
A. Executive Summary Overview	4
B. Background and Methods	5
C. Summary of Phase I Registry Participant Characteristics	6
D. Key Findings	7
E. Key Findings Linked To Research, Policy, and Practice Implications	
E1. Current VA Health Facility Experiences	
E2. Co-Morbidities	11
E3. Exercise	
E4. Skin Issues	13
E5. Post Traumatic Amputation Related Pain	14
E6. Pain Medication and Detoxification Care	15
E7. Drug and Alcohol Abuse Problems	16
E8. Mental Health	
E9. Prosthetic and Assistive Devices	
E10. Quality of Life	
E11. Family and Spousal Support	
E12. Peer Support	
E13. Educational and Career Paths	
E14. Work and Insurance Related Discrimination	
E15. Disability Changes and Concerns About Aging	
E16. Improving Outcomes	
E17. Life-Long Challenges of Combat-Related Limb Loss	
CITATION GUIDELINES	

#### A. Executive Summary Overview

This executive summary report is based on the following three reports prepared for the Amputee Veterans Project, managed by the Polis Center at Indiana University Purdue University Indianapolis for the Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research (IOCTARR).

- 1. Foote, Carrie E. and Regina Pessagno. 2010. *The Experiences of Vietnam Veterans with Combat-related Limb loss Phase II Findings*. Pp. 1-356.
- 2. Foote, Carrie E. and Regina Pessagno. 2010. *The Experiences of Vietnam Veterans with Combat-related Limb loss Phase III Follow-up Interview Findings*. Pp. 1-223.
- 3. Wolf, James. 2010. *Amputee Veteran Research (AVR)* Survey – Technical Report. Pp. 1-125.

#### **B.** Background and Methods

The Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research (IOCTARR) conducts policy-focused research on the various physical and mental health needs of veterans with combat-related amputations, also known as traumatic amputations. The aim is to help determine the best ways to implement the rehabilitation processes for traumatic amputees of present and future conflicts. Researchers at IOCTARR hypothesized that United States military personnel who experience an amputation resulting from combat are likely to have unique rehabilitation needs, especially over the life course. Most such needs are not well understood and are not adequately addressed. However, the multiplicity of conflicts the nation currently faces underlies the urgency of both better understanding and more comprehensive caring for such veterans. Indeed, the Department of Defense (DOD) now considers the goal of vastly improving the long and short-term rehabilitation of military personnel experiencing traumatic limb loss to be a critical issue. Despite this, little is known about the long-term outcomes of traumatic amputation arising from war. Without this information, the care of US personnel experiencing limb loss will remain less than optimal.

The Center received a funding award from the DOD in 2006 to examine these issues with Vietnam veterans who experienced combat-related limb loss (Grant#W81XWH-09-1-0375). Most such surviving veterans have lived with their amputations close to, or slightly more than, 40 years. Understanding their experiences, the basic thrust of the project, should shed substantial light on the nature of both the short and long-term needs of current combat-related amputees. The Amputee Veterans Research Project unfolded in three phases:

- Phase I developed a large data set of the Vietnam Veteran amputees (the registry database, N=453) who agreed to participate in various phases of the study. The registry collected demographic and injury-related information from each participant.
- Phase II collected in-depth interview data from a randomly drawn sample (n=20) of the registrants. These interviews probed participants' health and welfare needs during the first 12 months of injury and over their post-amputation lives.
- Phase III constructed a 159 item survey instrument administered to the entire registry to understand the health and care-giving issues associated with traumatic amputations. Nearly half of the men completed the survey (N=247<sup>1</sup>). Researchers also conducted interviews with two sets of respondents (follow-up interviews with fifteen of the original veterans interviewed in Phase II and a new sample of twenty veterans) to develop a keener understanding of survey results, especially around issues of social support.

This report provides an overview of the major findings from phase II and III as well as the research, policy, and practice implications of those findings. One phase of data, the new sample and qualitative findings around issues of social support, has not been analyzed and is therefore not included here.

<sup>&</sup>lt;sup>1</sup> A total of 263 veterans completed the survey. However, we were unable to verify the amputee status of nine veterans and we excluded another seven veterans who were missing digits only (fingers or toes). The final sample included in the data set was N=247.

#### C. Summary Of Phase I Registry Participant Characteristics

Tables 1 and 2 summarize the characteristics of the Phase I registry population. Importantly, the characteristics of the Phase III survey cohort that was drawn from the registry population showed no significant difference between the two groups. This suggests that the Phase III survey cohort findings are representative of the registry population.

Table 1 shows that all the registry participants
were male with an average age of 63 years.
Nearly all were White (89%) and the rest were
Black (4%), Hispanic (5%), and Other Race (2%).
Most were Army (57%) or Marine veterans (39%).
Just over a third (37%) were draftees. Ratings for
overall health were fair/poor (28%), followed by
good (36%), very good (28%), and excellent (8%).

Table 2 shows that the veterans reported a variety of health problems and injuries. Just over half (54%) reported stump pain, another 56 percent reported phantom pain, and 53 percent reported phantom sensation. About half (52%) also reported arthritis and back pain (48%). The veterans also reported depression (28%), PTSD (42%), head injury (17%), spinal cord injury (3%), broken bones (39%), and major burns (10%).

Characteristic (N= 453 Men)	%	Ν
Mean Age	63 Years	
Time Since Injury (mean/SD)	42+/-2 Years	
Age at Amputation (mean/SD)	21+/-3 Years	
White	89	403
Black	4	23
Hispanic	5	18
Other	2	9
Army	57	258
Marines	39	177
Navy/Air Force	4	18
Drafted	37	168
Enlisted	62	281
Health Excellent	8	38
Health Very Good	28	127
Health Good	36	160
Health Fair/Poor	28	127

 Table 1: Veteran Registry Population

Several men reported co-morbidities -- cancer (6%), diabetes (17%), heart disease (20%), overweight/obesity (25%), and neurological disorder (3%). Nearly 20% smoked cigarettes, and 7 percent reported alcohol and/or drug abuse problems. The majority had only a single amputation (69%), followed by double amputations (25%) and sustained triple or quadruple amputations (4%). The vast majority of the men were lower limb amputees (76%). Twelve percent were upper limb only and ten percent had upper and lower limb amputations.

Table 2: Health and Inj	ry Characteristics of Am	putee Veteran Registry Population
J J	J	

Characteristic	(%)	( <b>n</b> )	Characteristic	(%)	( <b>n</b> )
Head Injury	17	80	Phantom Pain	56	256
Spinal Cord Injury	3	15	Phantom Sensation	53	239
Broken Bones	39	177	Depression	28	129
Major Burns	10	46	PTSD	42	188
Smoking	18	82	Neurologic disorder	3	16
Alcohol/Drug Abuse	7	31	Use Prosthesis	81	366
Cancer	6	26	Single Amputee	69	313
Diabetes	17	77	Double Amputee	25	113
Heart Disease	20	90	Triple Amputee	3	14
Overweight/Obese	25	114	Quad Amputee	1	4
Back Pain	48	219	U Extremity	12	54
Arthritis	52	237	L Extremity	76	344
Stump Pain	54	246	UL Extremity	10	45

# **D. Key Findings**

- 1. VA Care. In general, veterans are satisfied with the care they currently receive from the VA. However, having a bad experience early on in life can deter some men from using the VA. In addition, long wait times to get an appointment, and once there to see a provider, continue to be of concern to veterans. Some of the veterans also perceive poorer quality of care at the VA when compared to private care for major health issues such as cancer care.
- 2. **Co-morbidities** that may be related to living with limb loss are a significant problem for combat-related amputees. These include cardiovascular conditions such as hypertension, heart attack, and angina; as well as diabetes, overweight/obesity, arthritis, and hepatitis C infection.
- 3. **Exercise.** A slight majority of Vietnam veterans with combat-related limb loss are not meeting the minimum physical activity guidelines recommended by the American College of Sports Medicine and American Heart Association. These guidelines recommend that adults either do "moderately intense cardio 30 minutes a day, five days a week or do vigorously intense cardio 20 minutes a day, 3 days a week." Barriers to exercise range from embarrassment of being seen in a gym, to difficulty of exercising because of a missing limb(s).
- 4. **Skin issues** among study participants have emerged as an issue of importance due to the high incidence of discomfort and pain this can cause which for some, leads to difficulty using a prosthesis. Self-care in the form of taking a break from prosthesis use to using ointments were reported.
- 5. **Pain** related to the amputation is a life-long problem and can be disabling when it occurs. Veterans experienced both direct limb loss related pain phantom and stump, as well as indirect from overcompensation of good limbs arthritis, shoulder, back, and hip pain.
- 6. **Detoxification Care**. Managing pain medication effectively, especially during the first 12 months of injury, was a major challenge for Vietnam veterans with combat-related limb loss.
- 7. Alcohol and Drugs. Veterans with combat-related limb loss may be more vulnerable to developing alcohol and drug abuse problems than the general population as well as veterans without traumatic injuries. This is because many of the veterans report using alcohol and/or drugs to self medicate as they sought to alleviate symptoms of PTSD and phantom or stump pain.
- 8. **Mental Health**. Veterans with combat-related limb loss are at risk for PTSD and depression. Although they are at risk for these mental health issues especially soon after their combat experience, such conditions can emerge at any time over the life course. Mental health care was virtually nonexistent for these men. Without care, many of these men's emotional health will suffer for years and some may develop alcohol dependency as a way to cope with symptoms (See key findings under alcohol above).

- 9. **Prosthetic and Assistive Devices.** Vietnam veterans with combat-related limb loss report high prosthetic use despite commonly experiencing difficulties learning how to use them, skin break down, and pain. Such problems appear to be outweighed by the benefits of using prosthetic devices which include gaining independence and mobility in addition to being able to function normally. Although most of the veterans clearly benefited from prosthetic use, using such devices was noted to be embarrassing by one veteran, thus highlighting the stigma surrounding physical disabilities and aberrant appearances. Finding a prosthetic device that fit well was also important, as veterans frequently noted that their mobility and ability were hindered until they found a prosthetic that fit them properly. Some resorted to using other assistive devices such as wheelchairs as they aged and anticipated greater reliance on wheelchairs. The problem of overcompensating was also brought to light, as one veteran noted that had he relied on an assistive device earlier on in his life it may have helped decrease the negative effect of overcompensation on his good limbs later in life. Most of the veterans in the follow up cohort also perceived positive aspects to newer prosthetic and assistive device technologies that are available to the veterans of current conflicts. It was noted by some, however, that these advancements also bring negative side effects, as they entail less physical man power and may therefore lead to a more sedentary lifestyle. Lastly, an important part of veterans' being able to successfully adapt to their disabilities and maintain a good quality of life lies in adapting cars and accommodating housing for those who suffer limb loss.
- 10. **Quality of Life**. Despite experiencing the traumatic effects of combat-related limb loss, most of the veterans reported a good quality of life. Most made the passage through important life-transitions, including finding meaningful long-term intimate relationships. They became fathers, found gainful employment, and had meaningful hobbies.
- 11. **Family and Spousal Support**. Families are critical sources of support for the veterans. Spouses especially played a pivotal role in facilitating the emotional and physical healing of the veterans. Many veterans in this study noted that spousal support is what made the healing process a positive one.
- 12. **Peer Support.** Peer support, especially in the form of peer counseling, provides critical emotional support for the veterans.
- 13. Educational and Career Paths. Vietnam veterans with combat-related limb loss have higher levels of educational attainment than the general population of veterans of all other wars. This higher level of education may be directly linked to their limb loss in that veterans were motivated to complete higher level degrees because of their limb loss and fear of not finding employment without a degree. Further, many veterans will want to stay in the military despite their limb loss.
- 14. Work and Insurance Related Discrimination. Some veterans in the interview cohort reported experiencing both work and insurance related discrimination in the early years following their injuries. They reported being denied work or insurance due to their limb loss. All of these experiences occurred early on, during the 1970s, before the ADA was passed.

- 15. **Disability Changes and Concerns About Aging.** The outcomes of the ADA, such as improved environmental accessibility have greatly improved the quality of life of Vietnam veterans. Yet, the natural aging process along with overcompensation of good limbs leads to decreasing mobility as the men approach their elder years. Many of the men report that their primary concern with aging centers around issues of maintaining mobility and independence.
- 16. **Improving Outcomes.** Several overlapping themes emerged in response to questions concerning how best to improve outcomes for veteran amputees from current conflicts. These themes included a range of attitudes, behaviors, support structures, and support services. Specifically, they included the ideas that amputee veterans need to maintain a positive attitude and accept what has happened to them. They also noted the importance of staying active, both physically and socially, in one's ability to adapt to traumatic limb loss. Having social support was also clearly important to the veterans, as they noted the positive impact that family members—especially wives/girlfriends—had on their lives. Sharing experiences with others in both a formal and informal setting could greatly improve emotional well-being. Having someone to talk to played a major role in the veterans' recovery and acceptance of their injuries. Lastly, obtaining a college education was also cited by the veterans as something that could play a major role in maximizing the positive outcomes of current amputee veterans' lives. Other less frequently mentioned themes included continuing prosthetic research, helping veterans stay in contact with other veterans, and insuring adequate services as the veterans aged.
- 17. Life-Long Challenges of Combat-Related Limb Loss. Most of the veterans in this study indicated that certain experiences they believed were associated with their combat-related limb loss were life-long challenges such as PTSD, managing physical disability that progressively gets worse as the veterans age, and traumatic amputation related pain.

#### E. Key Findings Linked To Research, Policy, and Practice Implications

The key findings from Phase II and III are briefly expanded on below with specific data from the survey and interview samples. Implications for research, policy, and practice are also briefly summarized here as they relate to each key finding. The 'survey cohort' findings refer to the findings from the survey sample. The 'interview cohort' findings refer to findings from the first set of interviews. The 'follow-up cohort' refers to findings from the follow-up interviews with most of the men from the interview cohort.

### E1. Current VA Health Facility Experiences

#### a. Key Findings

- 1. In general, veterans are satisfied with the care they currently receive from the VA. However, having a bad experience early on in life can deter some men from using the VA. In addition, long wait times to get an appointment, and once there to see a provider, continue to be of concern to veterans. Some of the veterans also perceive poorer quality of care at the VA when compared to private care for major health issues such as cancer care.
- 2. Although some of the veterans in the interview cohort were dissatisfied with care in their earlier years of recovery, most of the veterans who completed follow-up interviews reported currently using VA health care facilities and being satisfied with the care they received in recent years (n=10). Army veteran Eddie's comments were typical, "I've had a really good experience with the VA...the level of care, in my opinion has been excellent."
- 3. A few men in this cohort, however, expressed concerns about long wait times to both get an appointment, and once at an appointment, to see a provider during recent years. Army veteran Troy reported his experience, "there's still things that could be better [at the VA]. I had carpal tunnel surgery and for the pre-op, they actually tell you, you could be here from eight till four in the afternoon. Now that seems kind of ridiculous."
- 4. A few others had bad experiences in their early years of injury with VA care, which continues to deter them from VA care use today. Marine veteran Pete explained, "I don't want to go to the VA. I stay away from them as much as I can...I didn't like them when I came back in 1970. They never did anything that I thought was worthwhile...We weren't really treated very good. If you complained, you just got a shot of pain medicine to knock you out. So that was my experience with them and it just left a lasting impression."
- 5. Finally, two men from the follow-up cohort who expressed being currently satisfied with care, still expressed concerns about the quality of care at the VA when compared to private care for major health issues such as surgery. Army veteran Bob, for example, reported, "I mean, [if] I had cancer, I certainly wouldn't go to the VA to be treated for that."
- b. Research Implications
  - 1. More research is needed to understand factors that influence veterans' use of VA health care benefits.
  - 2. More research is needed to compare the quality of care for major health care needs (e.g., surgery) between the VA health facilities and non-VA facilities.

#### c. Policy Implications

1. VA health care should monitor wait times for appointments continuously as well as

monitor wait times to see care providers once an appointment has been made, in an effort to decrease barriers to VA Health Care.

- 2. Veterans should be provided with quality and care indicators of their local VA health care facilities so that they are making health care decisions based on current standards and practices of care, rather than making such decisions based upon care received in the early years following their injuries or possible misperceptions of the current quality of care.
- d. Practice Implications
  - 1. Providers should be educated about the frustrations experienced by their patients that center on perceived long-wait times and efforts should be made to make their wait more comfortable or to shorten their waiting time.

# E2. Co-Morbidities

- a. Key Findings
  - 1. Co-morbidities that may be related to living with limb loss are a significant problem for combat-related amputees. These include cardiovascular conditions such as hypertension, heart attack, and angina; as well as diabetes, overweight/obesity, arthritis, and hepatitis C infection.
  - 2. The survey cohort results indicate that based on self-reported disease based comorbidity, those in the participant sample are fairly healthy with relatively minor comorbidity. However, the highest disease prevalence is hypertension, with 68% of respondents indicating such a diagnosis . Other reported cardiovascular complications are much lower (previous heart attack 18%, angina 19%, congestive heart failure 3.7%). This is in contrast to the self-reported "heart disease" of the overall registry sample with a reported 20% heart disease prevalence. It is possible that respondents did not consider hypertension as a type of heart disease.
  - 3. Other co-morbidities that were high among the survey cohort were diabetes at 23% for the study sample which was slightly lower with the registry sample at 17%. Obesity was not very high with the study sample at 17% and slightly higher in the registry sample at 25%, but still below the national norm for this age group. Arthritis was extremely high for this population at 61% of study respondents and 52% of registrants.
  - 4. About half of the veterans in the follow-up cohort had difficulty maintaining their weight (n=8). For example, Army veteran Troy reported that "probably my biggest problem is packing more weight I guess and, you know, it's harder to get up and down and off with just the one leg." Five had heart conditions ranging from high cholesterol to heart attack.
  - 5. Two men in the follow-up cohort reported infection with Hepatitis C, which was not officially diagnosable until the early 1990s. One reported being cured.
  - 6. Six of the veterans in the follow-up cohort discussed increased problems with their good limbs and arthritis that they directly attributed to their limb loss and overuse of good limbs as they aged. For example, Army veteran Willy who mostly used a wheelchair said, "The most significant concession I've had to make due to my injury over the last 42 years is the fact that I have begun to limit myself because I've worn my left hand primarily out. I've just used it to push around with a wheelchair. I didn't get a power wheelchair until three, four years ago, four years ago, 2006, some 38 years after my injury."

- b. Research Implications
  - 1. More research is needed to understand the specific factors that account for, and prevent, deterioration (i.e., pain and arthritis) of good limbs as veterans age.
- c. Policy Implications
  - 1. As the veterans age and their health worsens, they may need to have their disability ratings redone to account for increasing disability that may occur as a result of limb loss and age.
- d. Practice Implications
  - 1. All veterans of current and past wars who sustained any kind of major injury that involved blood transfusions should be screened for Hepatitis C, and if positive for the virus, offered treatment.

### E3. Exercise

- a. Key Findings
  - 1. A slight majority of Vietnam veterans with combat-related limb loss are not meeting the minimum physical activity guidelines recommended by the American College of Sports Medicine and American Heart Association. These guidelines recommend that adults either do "moderately intense cardio 30 minutes a day, five days a week or do vigorously intense cardio 20 minutes a day, 3 days a week." Barriers to exercise range from embarrassment of being seen in a gym, to difficulty of exercising because of a missing limb(s).
  - 2. Just under half of the survey cohort (48%) reports engaging in less than 20 minutes of physical exercise a day that causes them to work up a sweat. Just under half (45%) also engages in at least 30 minutes or more of such exercise on a normal day, which meets the minimum recommendations.
  - 3. Overall, however, the study participants report a high level of exercise. Participants report a mean of 59 minutes per day of exercise and of these over 41 minutes is exercise that "works up a sweat" for almost five days a week (mean=4.67 days). Participants also report approximately 6.6 hours per day in sedentary activity.
  - 4. A few men in the follow-up interview cohort explained that their limb loss made it more difficult to exercise, which is one way to prevent weight and heart-related diseases. Barriers to exercise ranged from feeling too embarrassed to go to a gym due to their limb loss to the fact that limb loss made it more difficult to exercise because of the missing limb. Marine veteran Greg reported, "I've looked at joining a gym, and I haven't done that yet because it's sort of awkward to go in and do that sort of thing." Army veteran Ian also explained, "you're just not able to exercise as the normal person," which implies internalized stigma around limb loss. Further, many veterans mentioned that they did not start a regular exercise program until after they began to develop negative health conditions such as weight and heart problems.
- b. Research Implications
  - 1. More research is needed to understand the specific nature of barriers and facilitators to exercise among combat-related amputees.
- c. Policy Implications
  - 1. Policies that provide services and assistance for the combat amputee veteran should provide incentives or assistance to exercise, whether individually or as part of a formal exercise program. Such assistance should be offered over the life course.
  - 2. The VA should provide voluntary certification to public and private exercise facilities

that demonstrate their effectiveness in providing appropriate programs for amputee veterans.

- d. Practice Implications
  - 1. Providers need to emphasize the importance of exercise as a regular part of the veterans' activities over their life course. Regular exercise has significant potential to decrease weight related problems and heart conditions as the veterans age, as well as to decrease arthritis in good limbs.
  - 2. Providers should identify public and private exercise facilities where amputees regularly exercise and provide resources concerning these facilities to veterans. The veterans may be more likely to join such facilities where they will see other amputees like themselves.

### E4. Skin Issues

- a. Key Findings
  - 1. Skin issues among study participants have emerged as an issue of importance due to the high incidence of discomfort and pain this can cause which for some, leads to difficulty using a prosthesis. Self-care in the form of taking a break from prosthesis use to using ointments were reported.
  - 2. The survey cohort reported that within the past year 49% have experienced some type of skin breakdown at the amputation site with 61% reporting this caused pain or discomfort. Almost half of respondents (46%) reported "sometimes", "often", or "always" experiencing skin problems at their stump site, with 34% indicating this has interfered with prosthetic use. Of the 78 participants that reported this interference there was a mean of 28 days that they have not been able to wear a prosthetic over the past year. For the 149 veterans who had pain or discomfort at their amputation site due to skin problems in the past year there was a mean of 80 days of discomfort.
  - 3. All but one veteran in the follow-up cohort reported experiencing skin-related complications due to their prosthetic use (n=14). For most, these complications were minor skin irritations such as blisters and other sores on their stump that stem from the general use of a prosthesis. One had major problems that worsened with age as it became increasingly difficult to use a prosthesis. Marine veteran Greg explained, "I've got to be careful with wearing the prosthesis itself. I tend to have some skin breakdown on the inside of my artificial stump if I wear it too long. So there is some pain associated with that so I can't wear it as long as I used to. There's more discomfort now. Years ago I could wear it continuously without feeling anything. It's always been discomfort but I could deal with it and now it's getting more difficult to deal with." Another had skin problems resulting from a poor prosthesis fit, and three had complications with their initial stump healings that caused constant skin problems.
  - 4. Nearly all the men in the follow-up cohort used self-care techniques to manage such skin problems. Such techniques ranged from changing or fixing their prosthesis and taking a break from usage of the prosthesis to using medications or ointments (such as Lanoseptic and Bag Balm) to heal the sores. For example, Marine veteran Chris reported: "Well, finally I'll get off of it and soak the thing and then I clean the stump with Phisohex or a medicinal soap and try to stay off the leg. But I don't like to stay off the leg. I don't like to go out in public on crutches. I don't do it. I just have to stay off it until it heals or gets better and I don't like that. I don't like being broken

down in here for three or four, several days at a time but sometimes I have no choice because I just can't go on it." Only one veteran used preventative wound dressing. And only one sought medical care.

- b. Research Implications
  - 1. More research is needed to understand the specific ways veterans successfully manage skin conditions on their own without formal health care.
- c. Policy Implications
  - 1. Policies that provide services and assistance for the combat amputee veteran should recognize that the veterans may develop skin complications with prostheses use.
  - 2. Policies should continue to provide coverage for replacing or repairing a prosthesis that continues to irritate the veterans' skin or cause pain.
- d. Practice Implications
  - 1. Veterans with combat-related limb loss should be provided with self-care resources that may help with skin-related problems as most veterans may not seek formal care for such concerns.

# **E5.** Post Traumatic Amputation Related Pain

- a. Key Findings
  - 1. Pain related to the amputation is a life-long problem and can be disabling when it occurs. Veterans experienced both direct limb loss related pain phantom and stump, as well as indirect as a result of overcompensation of good limbs arthritis pain, shoulder pain, and hip pain.
  - 2. The survey cohort reported stump pain (85%), phantom pain (77%), and phantom sensation (76%). This was significantly higher than the registry cohort (54%, 56%, and 53% respectively), likely due to a more precise measure that used 'always experienced' and 'sometimes experienced'. Over 76% of survey participants report sometime or always having back pain. The category of "other pain" included such maladies as shoulder pain, neck pain, etc. and had a prevalence of 83% among the survey cohort.
  - 3. Nearly all of the veterans in the interview and follow-up cohort described and reported pain experiences related to their limb loss, including stump pain and phantom pain, some forty years after the initial loss of their limb(s). Marine veteran Chris recalled, "I had phantom pains unbelievable that hurt as bad as real pain. I still have phantom pain. It will almost take your breath. Even 43 years later."
  - 4. All of the veterans in the follow-up cohort also reported pain in other parts of their body that they mostly attributed to overcompensating with their good limbs and from an increase in the difficulty of using prostheses as they aged. Army veteran Ian, for example, explained, "The only thing I notice and I'm probably paying for early in life [is that] I seem to get more back problems now. And it could be because when you're an amputee you can't lift properly because you can't flex your knees and I notice I really have to watch it now or I'll get back pain."
  - 5. Two of these veterans reported using alcohol to manage phantom pain at some point in their lives, and subsequently developed alcohol abuse problems. "My drinking began as self-medicating dealing with phantom pains that just seem to trouble me in the evening," explained Army veteran Willy.

#### b. Research Implications

- 1. More research is needed to understand the neurological and social experience of pain over the life course for combat-related limb loss (e.g., What is the frequency of pain? How intense is it? Is there a neurological pattern? What pain management and coping mechanisms are successful? What effect does pain have on quality of life for the amputee and the amputee's social network? Do veterans from the current conflicts experience post amputation pain differently? Is the use of alcohol to manage phantom pain common among current veterans? Does pain increase over time?)
- c. Policy Implications
  - 1. Policies that provide services and assistance for the combat amputee veteran should recognize that amputation-related pain may persist over the life course and may exacerbate disability due to limb loss.
- d. Practice Implications
  - 1. The veteran amputees and their primary support providers, including care providers, should be aware that experiences with post-traumatic pain might be life-long and thus require life-long management and care.
  - 2. Providers should screen amputees who report phantom pain for possible use of alcohol to manage that pain, and if such use is occurring, providers should develop an effective pain management plan.

### E6. Pain Medication and Detoxification Care

- a. Key Findings
  - 1. Managing pain medication effectively, especially during the first 12 months of injury, was a major challenge for Vietnam veterans with combat-related limb loss.
  - 2. All of the veterans in the interview cohort reported experiencing excruciating pain following their initial injuries and thus received pain medication care. Problems arose with inadequate detoxification from, or curtailing reliance on, significant pain medication usage. Specifically, veterans often were not weaned carefully from prescription pain medications and at times were cut off abruptly. Sometimes, discontinuation was deliberate on the part of the care provider but other times sudden discontinuance was inadvertent and resulted from poor coordination and communication when being transferred between facilities. This failure caused unnecessary suffering, as the veterans had to manage withdrawal symptoms on their own. Marine veteran Keith explained, "That had to be the most negative, physical, medical treatment part of the whole first year that I had to deal with. I was addicted. They helped me there and then I had to go cold turkey...do you know how difficult that is?"
- b. Research Implications
  - 1. Research is needed to investigate whether current veterans with combat-related limb loss encounter similar experiences or if detoxification care has improved.
  - 2. There is a need to understand how veterans perceive the need for and management of pain medication, and to better understand the communication and coordination issues involved in providing pain management care.
- c. Policy Implications
  - 1. Policies regarding pain management should ensure that veterans receive better continuity of pain management care when being transferred between facilities or to different providers.

#### d. Practice Implications

- 1. The dispensation of pain medication should be carefully implemented during both the start-up and the completion phases of treatment. Particular care should be taken to ensure continuity of pain management care when transfers between facilities takes place.
- 2. Care providers and the veterans themselves should receive education surrounding prescription pain medication and efforts to discontinue such use should be closely monitored and occur gradually to avoid difficult withdrawal symptoms.

### E7. Drug and Alcohol Abuse Problems

#### a. Key Findings

- 1. Veterans with combat-related limb loss may be more vulnerable to developing alcohol and drug abuse problems than the general population as well as veterans without traumatic injuries. This is because many of the veterans report using alcohol and/or drugs to self medicate as they sought to alleviate symptoms of PTSD and phantom or stump pain.
- 2. Relatively few in the survey cohort reported smoking (15%). Even less survey participants reported currently having chronic problems with drugs and alcohol (7% as measured in their registry data). Six percent report using marijuana within the last year. Eleven percent indicated they had abused pain medication, however only 3.7% report it within the last year. Thirteen percent report using other illegal drugs besides marijuana at some time, but no participant indicated use within the last year.
- 3. Drug and alcohol abuse were significant issues for nearly half of the veterans in the interview cohort (n=9) during their early post-amputation years, and continues as a problem for a very small minority (n=3).
- 4. Most of these veterans attributed their problems directly to coping with distress, anxieties, and/or pain that stemmed from their combat and limb loss experiences (e.g., they used alcohol to self-medicate as a way to alleviate symptoms of PTSD and phantom pain). Army veteran Shawn reported, "there was no psychological help, nobody who cared...I started drinking, got into drugs." Similarly, Army veteran Willy reported, "my drinking began as self-medication dealing with phantom pains."
- 5. Yet despite experiencing such challenges, almost none mentioned having obtained drug/alcohol rehabilitation services of any kind during their immediate post-trauma care and re-integration into civilian life. A couple of men in the follow-up cohort shared informal means of dealing with ending/curbing drug or alcohol abuse. Army veteran Troy mentioned using medications to control cravings, "they gave me medications to control cravings," and Marine veteran Pete said being diagnosed with Hepatitis C led him to abruptly stop drinking, "I just quit drinking like I turned off a switch. Didn't crave it anymore."
- b. Research Implications
  - 1. More research is needed to investigate how Vietnam veterans with combat-related limb loss overcame drug or alcohol abuse problems, especially in the context of not receiving formal care.
  - 2. More research is needed to examine how the experience of Vietnam veterans with drug and alcohol abuse compare to the experiences of veterans of current conflicts. Do amputee veterans of current conflict experience similar drug and alcohol abuse problems? If so, do they receive care and does it help?

- c. Policy Implications
  - 1. Policies that provide for counseling and disability compensation for veterans should take into account that alcohol or drug addiction may occur in response to the veterans' combat or limb loss experience, and benefits and care should be allocated accordingly.
- d. Practice Implications
  - 1. Screening for drug and alcohol abuse and dependency, as well as educational programs aimed at reducing risks, should occur soon after the veterans start to reintegrate into civilian life and should be assessed periodically across the life course.
  - 2. Insuring access to mental health care and regular screening for mental health challenges may reduce the reliance on drugs or alcohol as a coping mechanism for limb loss and the combat experience.
  - 3. Insuring that veterans have access to knowledge concerning different ways to manage phantom pains may reduce the chance that alcohol will be used to self-medicate pain.

### E8. Mental Health

- a. Key Findings
  - 1. Veterans with combat-related limb loss are at risk for PTSD and depression, especially soon after their combat experience, but such mental health conditions can emerge at any time over the life course. Mental health care was virtually nonexistent for these men. Without care, many of these men's emotional health will suffer for years and some may develop alcohol dependency as a way to cope with symptoms (See key findings under alcohol above).
  - 2. The survey cohort reported PTSD (38%) and Depression (26%) as a chronic illness in their registry data. A scaled measure of current symptoms of PTSD showed a lower percentage of PTSD (13%), and a higher percentage of depression (33%).
  - 3. Nearly all of the veterans in the interview cohort reported experiencing severe mental health distress in the initial months and early years following their injuries. The reported distress ranged from severe depression to PTSD symptoms. Army veteran Roberto explained, "I went into a deep depression, a deep hole; I was just surviving from day to day." During the follow-up interviews, nine men currently reported having PTSD and depressive symptoms, one whom developed depression in recent years.
  - 4. The interview cohort also reported that mental health care during the initial months and early years following the veterans' injuries was non-existent, and a significant number received no formal care at any point over the life span. Army veteran Shawn reported, "there was no psychological help, nobody who cared."
  - 5. Importantly, some of the interview veterans who suffered from PTSD did not understand their symptoms and others viewed a PTSD diagnosis negatively. Further, symptoms of PTSD were not always immediately apparent and emerged at various times in the post-amputation life course, especially during major life transitions such as a divorce or retirement. Army veteran Frank explained, "I suffered from PTSD for years but I didn't realize it until I had an auto wreck…and I was in pain and suddenly I was retired. I was so busy during the working years that I didn't have time to think about anything else. But then all these things of Vietnam came rushing back and they didn't go away."

- b. Research Implications
  - 1. More research is needed to verify the incidence of self-reported PTSD through standard clinical assessment and to understand the occurrences, long-term effects, and experiences of living with PTSD. More research is also needed to understand how these men reached the self diagnosis of PTSD, especially during major life transitions such as divorce or retirement.
  - 2. More research is needed to identify both structural (e.g., limited availability of mental health care) and individual level barriers (e.g., negative perceptions of PTSD held by the veterans themselves) to mental health care among combat amputees.
  - 3. More research is needed to compare the level of reported mental health care received by amputee veterans of past and current conflicts to assess if mental health care has improved.
  - 4. More research is needed to learn about current veterans' perceptions of mental health afflictions such as PTSD and whether they have more or fewer negative views of mental illness than veterans of past wars.
  - 5. More research is needed to examine how the lack of mental health care in the early years, among those who report PTSD, affects the veteran's quality of life.
  - 6. More research can explore whether geographic disparities play a role in whether veterans will receive follow-up care in their futures.
- c. Policy Implications
  - 1. Screening for mental health illness, and the provision of appropriate treatment, should be part of routine health care from the beginning of post-amputation care and continued throughout the life course.
  - 2. More funding should cover the provision of interventions that successfully reduce barriers to mental health care among combat amputees, especially later on life.
- d. Practice Implications
  - 1. Providing information about PTSD and making referrals for mental health care as appropriate, should become standard procedure in the amputee veterans' program of care.
  - 2. Some of the veterans viewed PTSD negatively. Such perceptions may hinder them from being open about their mental health state or from seeking help if it is needed. Education should focus on the causes of PTSD and interventions to reduce the stigma around PTSD.
  - 3. Similarly, education around the different kinds of mental health services now available for veterans should increase use of such services.

# **E9.** Prosthetic and Assistive Devices

- a. Key Findings
  - Vietnam veterans with combat-related limb loss report high prosthetic use despite commonly experiencing difficulties learning how to use them, skin break down, and pain. Such problems appear to be outweighed by the benefits of using prosthetic devices which include gaining independence and mobility in addition to being able to function normally. Although most of the veterans clearly benefited from prosthetic use, using such devices was noted to be embarrassing by one veteran, thus highlighting the stigma surrounding physical disabilities and aberrant appearances. Finding a prosthetic device that fit well was also important, as veterans frequently noted that their mobility and ability were hindered until they found a prosthetic that

fit them properly. Some resorted to using other assistive devices such as wheelchairs as they aged and anticipated greater reliance on wheelchairs. The problem of overcompensating was also brought to light, as one veteran noted that had he relied on an assistive device earlier on in his life it may have helped decrease the negative effect of overcompensation on his good limbs later in life. Most of the veterans in the follow up cohort also perceived positive aspects to newer prosthetic and assistive device technologies that are available to the veterans of current conflicts. It was noted by some, however, that these advancements also bring negative side effects, as they entail less physical man power and may therefore lead to a more sedentary lifestyle. Lastly, an important part of veterans' being able to successfully adapt to their disabilities and maintain a good quality of life lies in adapting cars and accommodating housing for those who suffer limb loss.

- 2. Most participants (92%) report having a prosthesis with almost three quarters (72%) of these men wearing it for at least 12 hours on a typical day. Within the past year 49% have experienced some type of skin breakdown or rash at the amputation site and 61% reported pain or discomfort due to skin problems. Almost 46% reported "sometimes", "often", or "always" experiencing skin breakdown at their stump site, with 34% indicating this has interfered with prosthetic use. Participants report a mean of 28 days that they have not been able to wear a prosthetic over the past year as well as 80 days of discomfort due to skin problems.
- 3. Nearly all the veterans in the interview cohort used prosthetic devices, but with mixed results. For many, these devices helped them gain independence and provided a degree of normal movement, thus having a positive effect on their self-image. For example, Marine veteran Greg explained, "being fitted for a prosthesis was exciting because in a sense it gave us mobility and ability, and independence." However, learning to use prostheses was not always easy. Some veterans described difficulties with pain and skin problems because of using such devices. Army veteran Shawn illustrated these issues when he reported, "it hurts to walk, even with a prosthesis. It's not part of you. I had trouble learning to walk."
- 4. Some amputees in the interview cohort did not take advantage of newer technologies now available to OIF and OEF veterans. Others had to replace their devices several times over the life course due to wear and tear, while others had to resort to using other assistive devices such as wheelchairs as they aged Marine veteran David reported, "I used to use a prostheses but I haven't since '85 because they got too cumbersome. It just got too hard to walk with anymore."
- 5. Most of the veterans in the follow-up cohort had increased their use of assistive devices, such as wheelchairs, as they aged and many anticipated further increased usage of such devices. Reasons given for greater reliance on assistive devices ranged from increased difficulty in using prosthetic devices because of pain, decreased mobility as a result of aging, and stress on the body related to over-compensation of good limbs "Periodically, if my legs are so bad that I can't stand on them, I'll use crutches" (Marine veteran, Owen).
- 6. The use of assistive devices in public was embarrassing for some veterans in the follow-up cohort and could deter them from engaging in public activities, e.g., joining an exercise facility, even forty years after the injury. Marine veteran Chris explained, "Once in a while I resort to a wheelchair and I hate that. I don't go out in public with it or crutches either...I avoid using them in public." This highlights the continued

existence of internalized stigma around limb loss for some veterans.

- 7. The use of assistive devices on a regular basis, in conjunction with prosthetic use, may decrease injury to good limbs later in life. One veteran in the follow-up cohort wished he had relied on crutches more for things like getting in the shower, because if he had, he may have put less stress on his good leg by hopping without help "I learned my lesson too late. I hopped everywhere without bothering with my crutches. It would have been wiser to use my crutches because that is not good on my left knee" (Marine veteran Greg).
- 8. Most of the veterans in the follow-up cohort perceived positive aspects to newer prosthetic and assistive device technologies. However, a few also noted that some advances in assistive and prosthetic technology may have unintended adverse consequences. Several men mentioned the downfall of power chairs in that they require one to have a power lift for cars and they reduce the need for physical manual power; both factors increase sedentary lifestyles which may then result in poorer health. (The older chairs could be lifted by the men themselves and required some physical activity to move by the men). Army veteran Willy shared his opinion, "I can't imagine ever going full time to a power chair simply because of the health concerns at becoming a little bit more sedentary." Similarly, some of the newer prosthetic devices were viewed negatively (e.g., had to be charged at night, were only made for specific body types).
- 9. The importance of having a good prosthesis fit is critical. Several men in the followup cohort had problems with mobility and ability until they found a prosthesis with a good fit. Having a good fit went a long way towards normalizing the men's lives and fostering the idea that they could accomplish anything because they were able to maintain mobility – "If the prosthesis fits you can do pretty much whatever you want" (Army veteran, Eddie).
- 10. Adapting cars and housing for people with limb loss is critical to improving the quality of life of veterans with combat-related limb loss. Army veteran Jason explained, "We did take advantage of the Specially Adapted Housing grant back in '86 when we built the house that we're in now and so it's totally wheelchair accessible. I'm very appreciative of having that cushion behind me, you know, in case I need something I know it's there. It's a [grant program], with the VA."

#### b. Research

- 1. More research is needed to understand what is necessary to facilitate effective prosthetic use as well as the long-term effect on the body from using a prosthetic device.
- 2. Research is needed on reasons why aging veterans may move away from a prosthetic device later in life (e.g., obesity, other co-morbidities, impact of joints, too much hassle, and/or lack of support from the VA and other health systems related to communicating new technologies that might make it prosthetic use easier). What is the impact of the aging process on the ability or willingness to use a prosthesis?
- 3. More research is needed to identify which factors lead to increased usage of assistive devices as the veterans age, as well as what can be done to improve the experience of using prosthetic devices as veterans age.
- 4. More research is needed to better understand the barriers to using assistive devices in public places, such as internalized stigma, and to identify ways to reduce those barriers.

5. More research is needed to understand any adverse health effects of using newer technologies that may occur for the veterans, especially in terms of long-term health outcomes. Vietnam veterans did not have power wheel chairs or electronically controlled prostheses for much of their life so they engaged in more physical activity when using older devices. What are the long-term health outcomes of using newer as opposed to older technologies for veterans of current conflicts?

# c. Policy

- 1. Policies that provide assistance to replace prosthetic devices or that compensate for such devices, as well as other assistive devices, need to take into account that prosthetic and device use is a life-long experience and that as the veterans age, they may increasingly rely on additional assistive devices or need newer prosthetic devices that provide a better fit (limbs will change with age). Therefore, resources should be allocated to ensure that veterans of past and current conflicts have access to current state of the art technology later on in life if it is needed.
- 2. Adaptive cars and housing greatly enhanced the quality of lives of veterans. Such needs often increased as the veterans aged due to increased reliance on assistive devices. Policies that outline benefits to veterans for adaptive driving and housing need to take into account that such needs will increase with age regardless of the nature of limb loss.
- d. Practice Implications
  - 1. Interventions to assist veterans with combat-related limb loss to maximize positive outcomes over the life span should take into account that use of prosthetic devices is an on-going process. As technologies improve and the veterans age, they may benefit from interventions late in life to encourage their use and assist them with the better technologies or different kinds of assistive devices.
  - 2. At the same time, some newer technologies(e.g., power chairs) may lead to more sedentary lifestyles that can have adverse health outcomes. Plans should therefore be made to include a regular course of exercise for the veterans.

# E10. Quality of Life

- a. Key Findings
  - 1. Despite experiencing the traumatic effects of combat-related limb loss, most of the veterans reported a good quality of life. Most made the passage through important life-transitions, including finding meaningful long-term intimate relationships. They became fathers, found gainful employment, and had meaningful hobbies.
  - 2. The survey cohort completed a 12 item quality of life scale that examined their overall health;including several questions regarding whether their health limited a variety of functional activities, whether emotional problems had limited activities, and finally several indicators of emotional well-being. The majority (70%) rated their health as either very good or good, while only three percent rated their health as poor. For performing moderate activities, their health limited the men "a lot" and "a little" for thirty and thirty-eight percent of them respectively. Climbing several flights of stairs was problematic for a greater majority of the men with forty-eight percent reporting they are limited "a lot". The veterans were almost split on whether physical health limits their activities with forty-six percent stating yes and fifty-three percent stating no. However, a greater majority (59%) said that difficulties arise performing with

activities and work were not reported as being a major problem by the men. A minority of respondents (18%) had cut down on time spent on activities because of these problems and a quarter (25%) had accomplished less than they would have liked because of emotional problems. Social life was not affected much by either physical or emotional problems with almost three quarters (73%) stating that these problems interfere either "not at all" or "slightly". Most of the men (68%) reported being calm and peaceful either "always", "most of the time", or "a good bit of the time." A slightly smaller percentage (54%) recounted having a lot of energy at least "a good bit of the time". Feeling downhearted and blue happened for only fourteen percent of the men at least "a good bit of the time" while the majority (86%) reported feeling this way only "sometimes", "a little of the time", or "never".

- 3. All but one of the men in the follow-up interviews reported having a good quality of life, both overall and currently, and all attributed it to several factors. Specifically, they reported success in making the passage through several important life transitions that included finding meaningful long-term intimate relationships, having children and grandchildren, and making plans for, or already having gone through, retirement. They also reported being financially secure and engaging in a wide range of hobbies and community activities as factors that led to a good quality of life. Marine veteran Greg's comments illustrate a common experience among the veterans, "I think my quality of life has been good. I'm able to do anything I want to do. I travel, and have friends and family. Had a great job, a great career, over the years, able to retire, okay, from a good job. I have a nice home in a nice area. I just had a grandchild born in April. So I have two great kids and I have eight brothers and sisters and so my quality of life has been good from that perspective."
- 4. The veterans especially noted the importance of support from family, mostly their intimate partners, namely wives, as Army veteran Frank summed up, "I tell you, my wife's my angel. I don't know what would have happened without her." In the case of families, the men did specify ways family was important (these ways are reported below under family support).
- 5. It was not clear what factors predicted having successful relationships and engaging in meaningful activities, and whether they apply equally to amputees at all socio-economic levels.
- 6. The one man who expressed concerns with his quality of life centered on the inability to afford adaptive housing needs that emerged with decreased mobility as he aged (as opposed to focusing on relationships and other activities). He did not qualify for an Adaptive Housing Grant from the government because he was a single leg amputee " [My quality of life...] is not so good and it's because of the good leg getting bad on me. I just can't get up and hard charge like I usually do and that's been going on for some years and so that has a correlation to the mental health problem. You know, you get aggravated about the situation that brought it on and all that sort of thing. But you see I need things done in this house that would give me better access to the shower and that kind of thing and I can't afford it on what I collect from the VA. You know, I need a shower that I can get in without the risk of breaking my neck and I'm not eligible for that. And maybe if I went down and grumbled all the time they would do something, I don't know. But I read the law on VA and what they do and what they don't do and I don't find anything in there for it (Marine veteran, Chris).

- b. Research Implications
  - 1. More research is needed to explore what factors are important predictors of success in major life-transition experiences (e.g., marriage, parenthood, and career) for veterans with combat-related limb loss and whether amputee veterans of lower social-economic level and lower support fare as well.
  - 2. Research that examines the quality of life among veterans with combat-related limb loss should take into consideration the different meanings of "quality" for the individuals involved. For certain veterans it may refer to either relationship factors, financial factors or various hobbies and community activities, or mobility and ability factors. It is possible the veterans may experience different kinds or degrees of quality of life over the life course.
- c. Policy Implications
  - 1. Policies that cover grants for adaptive housing needs should consider widening eligibility for veterans with single limb loss who may have unique housing needs.
- d. Practice Implications
  - 1. Significant care providers, whether professional (e.g., medical personnel) or personal (e.g., spouses), need to be aware that veterans with combat-related limb loss will experience major life transitions such as marriage, parenthood, and steady employment. Losing a limb during combat does not necessarily mean such transitions will not occur.
  - 2. Exposure of newly injured veterans to veterans who have been living with combatrelated limb loss for some time and who have experienced some of life's major transitions, may serve as inspirational role-models in modeling that life can go on despite traumatic injuries (e.g., peer support).

# E11. Family and Spousal Support

- a. Key Findings
  - 1. Families are critical sources of support for the veterans. Spouses especially played a pivotal role in facilitating the emotional and physical healing of the veterans. Many veterans in this study noted that spousal support is what made the healing process a positive one. Many respondents identified it as the most important factor in their successes over the life course.
  - 2. The survey cohort reported having someone (such as a family member, spouse, or friend) available to talk to about problems at least some of the time (85%) as well as having someone to help at least some of the time if they are ill (91%). The majority of the survey cohort sample was married (81%) or living with a partner (2%) at the time they took the survey. The rest were divorced (9%), single living alone (4%), widowed (2%) and other non specified (2%).
  - 3. The interview cohort noted that families, especially wives, are critical sources of support for the veterans. Army veteran Frank explained the important companionship support his wife provided him when he first returned home, "My wife stayed with me for seven months in the hospital. She literally had to come in and eat breakfast, lunch and dinner off my plate so she had enough money to have an apartment and pay for the gas to see me. My wife and I are still together. She is probably the primary reason I made it."
  - 4. The veterans in the follow-up cohort identified their wives as being the most critical source of support today. Wives, and family are supportive in that they:

- a. Provide companionship and someone to talk to, "we're together 24 hours a day...need to talk to somebody, I can talk to her" (Marine veteran, David)
- b. Are someone in the veterans' lives who love and care for them, "We support each other and care about each other" (Army veteran, Eddie).
- c. Are someone who unconditionally understands physical limitations, "I was very fortunate in finding a young lady who was very understanding of my physical situation" (Army veteran, Jason).
- d. Are someone who helps with physical activities, "She was pretty much my legs...willing to help me with everything" (Army veteran Ian).
- e. Are someone who is tolerant and supportive during difficult times (e.g., alcohol addiction), "My wife has been inordinately a tolerant person. I went through a period of extreme use of alcohol...and she tolerated me during that period" (Army veteran, Willy).
- 5. The veterans in the follow-up cohort also identified past sources of critical family support during their early years of injury that included:
  - a. Providing them with a place to stay and/or financial support.
  - b. An amputee family member who, having adapted well to his limb loss, was a role model.
  - c. Someone who believes in the veterans and treats them as normal.
- 6. Several of the amputee veterans in the interview cohort went to great lengths to underplay their injury, seemingly resentful of any special assistance they received even though they still need (and in fact desire) substantial support, especially from their personal (e.g., family) care givers.
- 7. Some also noted the immense strain that being a spouse of someone with combatrelated limb loss caused in the marriage; in a few cases it led to divorce (though perhaps in conjunction with other factors).

# b. Research Implications

- 1. More research is needed to investigate issues regarding the nature of family social support from the perspective of the veterans and their primary support providers, especially how supportive roles may take on a greater responsibility and shift into a care-giving role over the life course.
- 2. More research is needed to better understand the nature of strain in veteran intimate relationships and ways identified to better support the primary support person.
- 3. More research could explore contradictory messages that veterans with combatrelated limb loss may exhibit and how best to manage them, from both the perspective of the veterans and their support/care providers.
- c. Policy Implications
  - 1. Some services for the veterans with limb loss should be extended to key significant others, such as the spouses or other main informal caregivers of the afflicted. Such provisions might include education services focused on limb loss issues and, in many cases, some degree of counseling and mental health services. Resources devoted to such caregivers continue to be an investment in the veteran, and one that may save money in the long run.
  - 2. Policies should be examined to ensure they emphasize both the need for independence as well as the need for support among combat amputees.

#### d. Practice Implications

- 1. The provision of information about the substantial difficulties that families of amputee veterans face should also become standard fare for both the veterans and their families. The physical and emotional challenges these families will confront are enormous and every effort expended to prepare them should help tremendously. Creative ways to support families should be explored (such as amputee veteran caregiver support groups).
- 2. Significant care providers, whether professional (e.g., medical personnel) or personal (e.g., spouses), need to be aware of, and find ways to accommodate the contradictory impulses that the veteran amputees will often exhibit. In short, a 'best practice' would be a balance of providing support while allowing for independence.

# E12. Peer Support

- a. Key Findings
  - 1. Peer support, especially in the form of peer counseling, provides critical emotional support for the veterans.
  - 2. The veterans in the interview cohort were virtually unanimous in extolling the virtues of peer companionship in their recovery and responding positively to limb loss "we were just brothers stuck in hell" (Marine veteran, Pete).
  - 3. Further, many of the veterans spoke forcefully of their desire to stay connected over the life course with those who participated in, or befriended them during, their war/healing experiences.
- b. Research Implications
  - 1. More research should examine the vital role of peer social support, both from the perspectives of the veterans and their peers (during the recovery process, integration into the community, and quality of life over the life span).
- c. Policy Implications
  - 1. Policies should be developed to support different ways to stay connected with military peers such as through volunteer opportunities, military organizations, as well as to support the veterans to develop skills and the means to do so -- if continued military service is not an option or is not pursued. Digital technology, especially social networking media, might be particularly resourceful in developing different options to stay connected.
- d. Practice Implications
  - 1. The rehabilitation and care efforts will often be significantly enhanced if the exposure to peers (i.e., other veteran amputees) can be incorporated into other pre or post-treatment experiences. For example, the veterans in this sample observed that:
    - a. Peers can serve as a comparison group thereby sensitizing the veteran to the very realistic perspective that their injuries could have been worse "there were so many a lot worse off that I was" (Army veteran, Troy).
    - b. Peers can help reduce stigma associated with limb loss by showing the veteran that he/she is not alone in having to sustain such injuries and their associated life changes, -- "You know it really wasn't that bad. I seldom saw any veterans that really were down. I mean they were making the best of a bad situation" (Army veteran, Ian).
    - c. Veteran peers from past wars can serve as role models or counselors for veterans from current wars. This can provide the past war veteran with a

chance to share their experiences while it provides the new veteran with the benefits of being helped by someone who is (or has been) in their situation. For example, peers can provide guidance and support to encourage the veterans to access needed services (especially mental health care) – "I tell kids that come back from Iraq and he says well I'm having problems sleeping and I say, go get some counseling. Go talk about your problems because if not, it will be there for the rest of your life" (Marine veteran, David).

- d. Peer counselors allow veterans a safe space to share their experiences and stories and can help with emotional health, -- "I think a lot of [what helps] is peer counseling, kind of amputees getting together and talking and sharing their experiences because it's nice to hear that other people have the same thoughts and feelings and aggravations and challenges and how they cope with them" (Army veteran, Eddie).
- 2. Facilitating contacts between the amputee veterans under treatment and specific 'peers' and other non amputee veterans that the amputee came to know during the initial phases of their ordeal may also provide additional recovery benefits.

# E13. Educational and Career Paths

- a. Key Findings
  - 1. Vietnam veterans with combat-related limb loss have higher levels of educational attainment than the general population of veterans of all other wars. This higher level may be linked to their limb loss in that veterans were motivated to complete higher degrees because of their limb loss and fear of not finding employment without a degree. Further, many will want to stay in the military despite their limb loss.
  - 2. The survey cohort reported 14% of the men had a high school diploma or less, 31% had some college, 34% had a bachelor's degree, and 21% had advanced degrees. The 2007 American Community Survey compared educational attainments of U.S. war veterans of multiple war periods (e.g., Gulf War 1 and II, Vietnam, Korean and WWII). Those who served in multiple war periods (more than one war) had the highest level of attainment (median age 54 years) with 26% at the high school level, 41% with some college, 17% with a bachelors degree and 16% with advanced degrees. Yet, our cohort fared better.
  - 3. All of the veterans in the interview cohort had their envisioned career paths abruptly interrupted. Such paths included those of some veterans who had planned to make a military career when they joined the military, -- "I wanted to stay in the Marine Corps" (Marine veteran, Chris). As a result, such veterans were devastated when they were forced to retire due to their limb loss. That said, all the veterans in this sample reported gainful employment for much of their civilian life.
  - 4. Importantly, several veterans in the interview cohort mentioned that their limb loss was one of the main motivating factors for them to return to school and obtain a college degree. Army veteran, Nick explained, "I know my injury is what drove me to go to school and get an education. I am not sure that I would have gone to college, had I just had a job and worked my way up that way."
- b. Research Implications
  - 1. More research is needed to explore how veterans with combat-related limb loss positively adjust to the realization that their career goals may be dramatically altered due to limb loss.

- 2. More research could also explore how career goals of veterans are impacted by a variety of kinds of traumatic injuries (e.g., limb loss, traumatic brain injury, major burns).
- c. Policy Implications
  - 1. Policies should continue to allow for accommodations such that amputee veterans can continue to serve in the military if they so desire. Having the option to stay in the military may aid in the recovery of those veterans who wish to continue to serve.
  - 2. Policy makers should explore whether policies that provide financial support for combat veterans to pursue higher degrees might provide additional financial educational support for those who sustain traumatic injuries such as limb loss because of the effect of such limb loss on career options (e.g., special scholarships for veterans with traumatic injuries).
- d. Practice Implications
  - 1. A greater emphasis might be given to providing information about higher education options, as well as appropriate advising (e.g., how to apply, degree choice, financial options) in the rehabilitation plan of those veterans with combat-related limb loss who lack a college degree.

# E14. Work and Insurance Related Discrimination

- a. Key Findings
  - 1. Some veterans in the interview cohort reported experiencing both work and insurance related discrimination in the early years following their injuries. They reported being denied work or insurance due to their limb loss. All of these experiences occurred early on, during the 1970s, before the ADA was passed.
- b. Research Implications
  - 1. Discrimination today is more likely to occur in the area of health disparities and more research should explore this issue among current veterans (e.g., access to care). We should not simply assume work or insurance related discrimination does not exist because we now have legal remedies. More research can be done to explore whether work or insurance related discrimination continues to persist among combat amputees, perhaps in less obvious ways.
- c. Policy Implications
  - 1. The 1990 American with Disabilities Act would make the experiences described in this report illegal today and less likely to occur. However, more subtle forms of discrimination may continue to exist.
- d. Practice Implications
  - 1. Programs geared towards helping military personnel with combat-related limb loss should include assessing whether they experience any form of discrimination as well as interventions that could help veterans manage and address such unequal treatment if it does occur.

# E15. Disability Changes and Concerns About Aging

- a. Key Findings
  - 1. The outcomes of the ADA, such as improved environmental accessibility have greatly improved the quality of life of Vietnam veterans. Yet, the natural aging process along with overcompensation of good limbs leads to decreasing mobility as the men approach their elder years. Many of the men report that their primary concern with

aging centers around issues of maintaining mobility and independence.

- 2. Several of the men in the follow-up interviews reported positive changes in the form of environmental accessibility as a result of the ADA, improvements with the auto-industry in providing hand controls at no cost, and improved societal attitudes of people living with limb loss. Each of these factors improved the quality of the men's lives as they aged. For example, Army veteran, Willy commented on the improved societal attitudes, "Oh goodness yes [people's attitudes have changed toward disabled people]. People are much more receptive of it. I mean it's not that big a deal...It's also adults recognize that it's a teaching opportunity for their children. Thirty years ago if a child pointed at me and said look that guy doesn't have any legs, his momma more than likely was to grab him by the hand and shush him and take him around and giving him a talking to that he shouldn't point in public and this sort of thing. Nowadays the parents are much more likely to say well why don't you go ask him what happened to him or [I'll] say come here I'll tell you what happened to me. So it's usually a teaching opportunity and everyone wins for it. The parents win, the child wins, and I win simply because we're not something, we're all curious."
- 3. The primary concerns the men in the follow-up cohort had about aging centered on how to maintain mobility, fear of increasing loss of independence due to their limb loss, and older age health issues. Army veteran, Eddie, explained, "the older we get things just start wearing out and that's probably the concern I have. The aches and pains are just going to increase and the variety of them and the intensity [will increase too]. So that's the only real concern I have is the deterioration of [my body because] of age."
- 4. Half the men in the follow-up cohort also mentioned decreased mobility and ability as they aged and nearly all attributed these changes to the natural process of aging and not a factor uniquely related to their limb loss. However, this contradicts some other findings in the physical health and devices findings section where the men clearly indicate greater difficulty with mobility that they attribute to factors related to missing a limb.
- b. Research Implications
  - 1. More research is needed to understand how structural and individual level interventions and change (such as the ADA and improved societal attitudes) help improve the quality of lives of veterans with limb loss.
  - 2. More comparative research is needed to document whether the veterans' perception regarding their decreased mobility and ability is solely due to the natural process of aging, or is exacerbated by their limb loss.
- c. Policy Implications
  - 1. Policies that aim to eliminate structural barriers to accessibility, as well as directly intervene to improve people's attitudes towards people with disability, will likely continue to improve the long-term quality of life outcomes of veterans with limb loss.
  - 2. Policies related to aging should relate to awareness of how limb loss affects aging with flexibility to accommodate any needs unique to this population.
- d. Practice Implications
  - 1. The veteran amputees will benefit from learning and being encouraged to use assistive technologies that may help them maintain their mobility as they age.
  - 2. The veteran amputees will benefit from being reminded of the importance of exercise in maintaining mobility and ability as they age.

#### E16. Improving Outcomes

- a. *Key Findings:* 
  - 1. Several overlapping themes emerged in response to questions concerning how best to improve outcomes for veteran amputees from current conflicts. These themes included a range of attitudes, behaviors, support structures, and support services. Specifically, they included the ideas that amputee veterans need to maintain a positive attitude and accept what has happened to them. They also noted the importance of staying active, both physically and socially, in one's ability to adapt to traumatic limb loss. Having social support was also clearly important to the veterans, as they noted the positive impact that family members-especially wives/girlfriends-had on their lives. Sharing experiences with others in both a formal and informal setting could greatly improve emotional well-being. Having someone to talk to played a major role in the veterans' recovery and acceptance of their injuries. Lastly, obtaining a college education was also cited by the veterans as something that could play a major role in maximizing the positive outcomes of current amputee veterans' lives. Other less frequently mentioned themes included continuing prosthetic research, helping veterans stay in contact with other veterans, and insuring adequate services as the veterans aged.
  - 2. The follow-up cohort reported what they perceived as the most important success factor to their doing well in life. They also reported on their perceptions of what could be done to improve the long-term outcomes of today's veterans who experience combat-related limb loss. Finally, they described advice that they would give veteran amputees from current conflicts in terms of maximizing positive outcomes for them. Several overlapping themes emerged in response to these inquiries and included a range of attitudes, behaviors, support structures, and support services. These included the importance of:
    - a. Having a positive attitude and self-determination, -- "[My most important success factor has been] the ability to do what I want to do with a mindset that I can accomplish anything I want" (Marine veteran, David).
    - b. Accepting what happened, staying active and engaged with social activities and people, and exercising/engaging in physical activities, -- "Well, I just accepted that this happened and I have to deal with it and move on with life and adapt to whatever physical things I had to do" (Army veteran, Bob).
    - c. Having people who support you in terms of perceiving ability rather than disability, -- "The only thing that holds you back is people that think you can't do it" (Army veteran, Troy).
    - d. Having a supportive family, especially an intimate partnership such as through marriage, -- "My wife, I don't, if I would not have had someone so understanding and willing to help me with everything and to listen to my complaints and really never, never complained about me having a disability. That's probably been the biggest [success] factor (Army veteran, Ian).
    - e. Being able to share your experiences with others, especially mental health counselors, fellow amputee veterans, and wives. Army veteran, Shawn, illustrated this important factor when he stated, "Well, I would say [the one thing] that benefited me the most was when I got into counseling with the one psychiatrist. She was the biggest help that turned me around...She didn't give up on me. Because it was a hard thing to admit that you killed somebody. It

was a hard thing to admit that you had this guilt over it. You know, you can't go through life feeling guilty."

- f. Getting an education. As Army veteran, Ian reported, "The second biggest factor [to my doing well] probably was me going back and finishing my college education. I, being truthful to myself, if I had not been injured I don't know if I would have gone back to college. But because of my injury I felt that I had to get a college education and be able to get a desk job and I was able to do so."
- 3. Other less commonly mentioned factors that may improve outcomes included:
  - a. Allocating more resources to further improve prosthetic research.
  - b. Facilitating ways for veterans to stay in contact with other veterans.
  - c. Insuring adequate services later on in life that might relate to the loss of function in the good limb.
- b. Research Implications
  - 1. More research is needed to understand how each of these factors work to improve long-term outcomes of living with combat-related limb loss, as well as which factors are most predictive of improved outcomes.
- c. Policy Implications
  - 1. People who make policies that affect veterans should be aware that a multitude of structural and individual level factors affect various aspects of the veterans lives and that different groups who work to address different needs (e.g., mental health, education, family relations) should work together such that policies address the entire spectrum of the veterans' lives.
- d. Practice Implications
  - 1. Providers must be aware of the multitude of policies that affect veterans over the life course and learn how to negotiate among them for the benefit of the veteran.

# E17. Life-Long Challenges of Combat-Related Limb Loss

- a. Key Findings
  - 1. Most of the veterans in this study indicated that certain experiences they believed were associated with their combat-related limb loss were life-long challenges such as PTSD, managing physical disability that progressively gets worse as the veterans age, and traumatic amputation related pain. Army veteran Ian's experience was typical, "I get phantom pain quite often, on average three times a week." Army veteran, Frank's experience was also typical of folks who continued to experience mental health issues forty years past their injuries and combat experiences. Frank explains, "I've been [receiving treatment for PTSD for several years now]. 2001 I was in-house for eight weeks and I've had about three 12-week sessions since then. [And the] PTSD is bad. I live with that every day. [So] personally for me [my emotional health is] not real good."
- b. Research Implications
  - 1. More research is needed to better understand how these issues manifest as veterans age (e.g., Do they have to retire early? Are they spending more time in the health care system?).
  - 2. It is unclear how this finding compares with non-military individuals with traumatic limb loss injury or with military veterans who sustain other kinds of traumatic injury such as major burns or traumatic brain injury. More studies are needed which,

- a. Compare the experiences revealed in this report with those of male (and female) amputees whose limb loss occurred in civilian life.
- b. Compare the experiences revealed in this report with those of other veterans who sustained different kinds of traumatic injury.
- 3. All of the issues explored in this study, as well as relevant issues not addressed in this sample, should be probed further concerning veterans with combat-related limb loss of more recent conflicts.
- c. Policy Implications
  - 1. Policies that provide services and assistance for the combat amputee veteran need to take into account that specific issues related to the effect of experiencing both combat and major limb loss (such as PTSD, physical disability, and phantom pain) may persist over the life course.
- d. Practice Implications
  - 1. Healthcare professionals may have education regarding care for the elderly but may lack information about the disabled elderly. Professional and support networks should be educated to understand and assist with life-long problems associated with traumatic limb loss.

#### CITATION GUIDELINES

Please use the following when citing this report:

Foote, Carrie E., Regina Pessagno, and Robbie Janik. 2011. *Executive Summary Amputee Veteran Project Phase II and III. Pp. 1-31.* Report prepared for the Amputee Veterans Project, managed by the Polis Center at Indiana University Purdue University, Indianapolis for the Indiana-Ohio Center for Traumatic Amputation Rehabilitation Research (IOCTARR).

Researchers may request to use portions of the findings from this report and the reports on which it is based to develop peer-reviewed articles for publication and presentation. For permissions and citation requirements, contact IOCTARR c/o the Polis Center (317-274-2455).