

Survey of Veterans with limb loss finds many positives, despite serious health issues

More than 2,500 living Vietnam Veterans and more than 1,000 Iraq and Afghanistan Veterans have suffered major traumatic limb loss. How is their overall health? What are their most pressing medical concerns? How have they adjusted to their prosthetic limbs, and how satisfied are they with the technologies available to them? What can VA do to further improve their quality of life?

These and other questions were addressed by a recent VA survey of 581 Veterans and service members representing both eras. The findings appear in the *Journal of Rehabilitation Research and Development (JRRD)*, found on the Web at www.rehab.research.va.gov/jour/10/474/contents.html. Overall, write the researchers, “The men and women from both conflicts who completed our

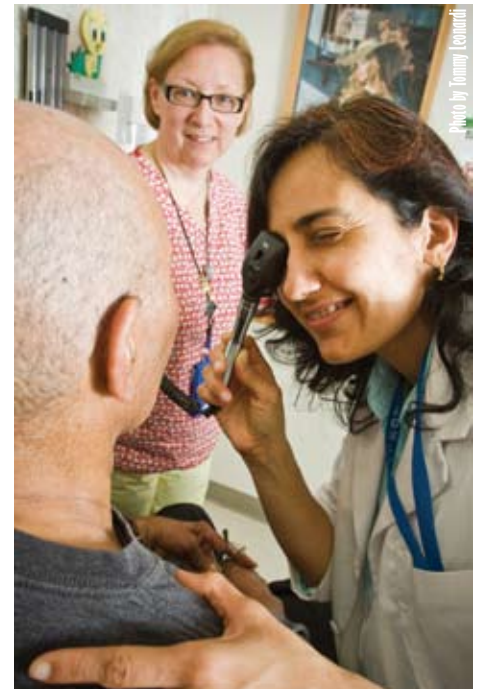
survey report favorable health and quality of life ratings, tremendous resilience, and hard work to reintegrate into society despite serious injuries and comorbidities.”

Gayle Reiber, MPH, PhD, an epidemiologist at the Puget Sound VA Health Care System, was lead investigator on the survey. She also helped coordinate a 27-member panel—including experts from VA, the Department of Defense and academia, as well as Veterans with limb loss—who played a key role in interpreting the study findings and forging recommendations for VA concerning amputation and prosthetics care. Reiber spoke with *VA Research Currents* about the survey results and related issues.

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Dr. Gayle Reiber was lead investigator on a survey of 581 Veterans with limb loss.



Nurse practitioner Jyoti Desai (right) and nurse Barbara Murphy collaborate on patient care.

New model of primary care being studied across VA

Army Veteran Gena Van Camp has been using VA health care for 30 years. She’s more satisfied nowadays than she was a few years ago, especially with her primary care.

In the past, says Van Camp, she would often be seen by a medical resident. Now, it’s the same nurse practitioner every visit. To Van Camp, that means someone who knows her and her medical history, without needing to look through her VA electronic health record.

“Before, it was a new doctor every few months,” says the Coatesville, Pa., resident, who served in military

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Actors in study reveal doctors' failings to tailor care

Patients often receive inappropriate care because their doctors fail to tailor care plans to their individual circumstances, according to an innovative study by a team with the University of Illinois at Chicago and VA's Center for Management of Complex Chronic Care.

The VA-funded research, published July 20 in the *Annals of Internal Medicine*, is the largest study of physician performance ever conducted using actors presenting in medical offices as real patients.

"Physicians did quite well at following guidelines or standard approaches to care, but not so well at figuring out when those approaches were inappropriate because of a particular patient's situation, or life context," says lead author Saul Weiner, MD.

The study used actors trained to simulate real patients to complete and audio-record 400 visits to a wide range of physician practices in Chicago and Milwaukee, including several VA sites, between 2007 and 2009. At each clinic, identities, medical records and insurance information were



Checking up on doctors—Dr. Saul Weiner (left) led a study exploring how well physicians tailor care according to patients' individual circumstances.

created for the actor patients. The doctors had all agreed to participate but were not told which patients were actors.

The actors followed scripts that contained hints—"red flags"—of significant biomedical or other issues that should have cued doctors to individualize care accordingly. For example, in a case involving a 42-year-old man complaining of worsening asthma, the actor mentioned both a biomedical red flag (coughing at night) and a contextual red flag (losing his job) that suggested acid reflux and loss of health insurance, respectively, as key parts of the problem that should have been addressed in the care plan. If the physician failed to pick up on such flags and alter care accordingly, the researchers considered the resulting care plan inappropriate.

For visits where individualizing care required an alternative to the customary treatment of the patient's main complaint, only 22 percent of physicians provided error-free care during a contextually complicated encounter, 28 percent during a biomedically complicated encounter, and 9 percent during an encounter with both contextual and biomedical red flags.

"To date, measures of doctors' performance have focused on situations where knowledge of the individual patient wasn't critical," says Weiner. "Under those conditions, physicians did fairly well. But as soon as care required more than following an algorithm—finding out what's really going on with a patient and acting on that information—only a minority of physicians got cases right."

The study also found that physicians were more likely to respond to the biomedical rather than contextual red flags, even when both were equally important to planning appropriate care. "We believe that reflects the way in which physicians are educated," says Weiner. "The lesson here is that there has to be a dramatic change in the way we train physicians." —

'Physicians did quite well at following guidelines or standard approaches to care, but not so well at figuring out when those approaches were inappropriate because of a particular patient's situation, or life context.'

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communications. “By the time someone got to know you, he was gone.”

Van Camp also likes the practice’s accessibility. When she calls on the phone, a triage nurse listens to her concern and either provides appropriate advice or recommends an appointment. When Van Camp does need to leave a message, she gets a return call promptly.

The changes Van Camp is seeing are part of a shift in VA to a new way of doing primary care. It’s called the patient-centered medical home (see box on page 6). Actually, the model isn’t new—it’s been around since the 1960s—but it’s receiving renewed attention, both in and outside VA. This spring, VA researchers began evaluating how it can be best applied in VA’s health system, the nation’s largest.

Transformation already under way

A handful of VA clinics began moving to the new model a year or two ago. VA policymakers say at least 80 percent of VA clinics will follow suit by 2012. The rollout is a huge effort—even by VA standards—that is costing some \$250 million. It’s expected to pay long-term dividends, though, across several areas, such as patient outcomes, provider satisfaction, and organizational efficiency. Among the core features: team-based care that emphasizes continuity; a bigger role for nurses in coordinating care; email, secure messaging and other alternative forms of contact with patients; and more attention on behavioral health issues.

The makeover across all VA sites should be complete by about 2015. “It will take that long because it’s also a culture change,” says Joanne Shear, MS, FNP-BC, who worked as a nurse practitioner in VA and is now helping to oversee the transition for VA’s Office of Patient Care Services. The culture change, she explains, has to do with the mindset at the philosophical core of the medical home. “It’s about being more patient-centered,” says Shear. “In reality, we’ve always tried to accommodate what the patient wanted. But we’re now placing more emphasis on that. We want to focus on what the patient wants, not what the facility wants them to have.”

Beyond that general tenet and some others, there’s a lot of discussion about what exactly the medical home should look like in VA. That’s where VA researchers come in.



Photo by Tommi Leonard

No place like home—Barbara Murphy, RN, checks Veteran Hyslof L. Jones’ blood pressure during his regular visit to the Philadelphia VA Medical Center’s primary care clinic, based on the medical home model.

Five teams of top VA health-services researchers in five different regions have begun a wide-reaching study of the medical home model. The effort will take three to five years. The teams will address a complex array of issues, drilling down to the details of day-to-day care. But they also hope to shed light on overarching questions: How should the model be structured in VA? Which features work best for VA patients? Is it economically viable? Are patients—and providers—happier?

David Atkins, MD, MPH, associate director for VA’s Health Services Research and Development Service, worked with Patient Care Services to develop and select the research sites. He says the

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VA Research Currents: A couple of the articles in this issue of *JRRD* talk about a paradigm shift in VA amputation and prosthetics care. What is changing?

Dr. Reiber: Dr. Barbara Sigford [VA's recently retired national director of physical medicine and rehabilitation] outlines the changes in her editorial. Basically, it's an extension of what has been happening in the Department of Defense. We're moving toward care that is very person-centered, evidence-based, comprehensive and holistic. It's delivered by a team including medical professionals, therapists, prosthetists, mental health specialists, and other specialists as needed. There is a greater emphasis on continuity of care throughout the Veteran's lifetime, with the goal being to provide regular, ongoing checkups to continually reassess function, satisfaction and the management of mental and physical health problems. We are also committed to ensuring that Veterans will be able to readily review the latest prosthetics technology. We want to restore the person to his or her maximum level of function and maintain function over time.

Does the paradigm shift also involve changes in infrastructure? Yes. We are creating a tiered system of care that is similar in some ways to our polytrauma system. The new Amputation System of

Prosthetics resources online

JRRD's special issue on prosthetics contains a comprehensive guide to resources for service members and Veterans with limb loss, and for their families. To view the guide, visit www.rehab.research.va.gov/jour/10/474/pdf/mcfarlandappen.pdf.

Another important resource is the VA Prosthetic and Sensory Aids website, at www.prosthetics.va.gov.

What did the prosthetics survey find?

Below is a sampling of the survey findings reported in *JRRD*'s recent special issue on limb loss and prosthetics. See more at www.rehab.research.va.gov/jour/10/474/contents.html.

	Vietnam	OEF/OIF
Number of Veterans completing survey	298	283
Percentage of respondents with multiple limb loss	24	22
Percentage of unilateral lower-limb amputees currently using a prosthesis	84	94
Percentage of unilateral upper-limb amputees currently using a prosthesis	70	76
Percentage satisfied with their prostheses	80	88
Percentage rating their overall health as excellent/good	71	86
Percentage reporting phantom-limb pain	72	76
Percentage reporting PTSD	38	59
Percentage reporting depression	25	24
Percentage reporting hearing loss	47	47

Care consists of Regional Amputation Centers, Polytrauma Amputation Network Sites, Amputation Care Teams, and Amputation Points of Contact. The goal is to provide specialized, expert care as close to home as possible for our Veterans with limb loss. The system was funded by VA in 2009 and should be fully in place by the end of this year.

How are VA and DoD cooperating in this area? Our DoD clinical colleagues have been very helpful. Overall, we've done a good job of transitioning service members with limb loss from DoD to VA. But there are still areas needing work. For example, medical records are not completely bidirectional at this time. The Bi-Directional Health Information Exchange is limited in transferring inpatient and imaging data, which is a problem for polytrauma patients moving between agencies.

In the survey, surprisingly, most respondents rated their overall health fairly high. At the same time, many of them reported serious health problems, such as chronic pain. How do you explain that?

There's a lot of resilience and can-do attitude in this group of service members and Veterans. We certainly didn't expect to find higher self-rated health scores among those with multiple limb loss, compared with those with unilateral upper- or lower-limb loss. But members of our expert panel think this may be due to these patients' near brush with death. It would appear that they, in particular, are very happy to be alive and able to function, and this is reflected in how they rate their overall health.

How well are the majority of respondents functioning in everyday life? Among those with unilateral lower-limb loss, for example, only a very small percentage do not walk. In Vietnam Veterans with unilateral lower-limb

loss who uses prostheses, about 20 percent take part in low- or high-impact activities, such as sports or farming chores. For OEF/OIF Veterans in this group, the figure is about 52 percent. This is a victory in terms of allowing people to be active. They don't have to give up things that are an important part of their lives, such as walking, running, gardening and working around the house. Also, when we asked the Veterans whether they can cope with their prostheses, and whether they've adjusted to life with a prosthesis, a large majority responded positively. Also, a large percentage are married, have children and are working or going to school. Overall, these findings are very good news. Of course, there are still areas where we can improve.

What's an example of an area in need of improvement? Pain is a huge problem. We found a high prevalence, and this jibed with clinicians' impressions. I wouldn't want to go through life with the phantom limb pain, residual limb pain or chronic back pain these folks endure. These are disabling conditions. We need more research, more aggressive approaches to see if we can alleviate the pain. Also, the frequency of skin problems in Veterans using prostheses is high: 51 percent of Vietnam and 58 percent of OEF/OIF Veterans are regularly bothered with skin problems such as ulcers. This limits their function and options such as going to work. Many of our findings identify areas where we might be able to make things better through research.

Most Veterans say they're satisfied with their current prosthesis—80 percent of Vietnam Veterans and 88 percent of the OEF/OIF group. At the same time, a significant number—41 and 45 percent, respectively—say they'd want to change their current model for another. How do you reconcile that? There are many people who are satisfied with their current



In the swim—Army National Guard Veteran Karl Dorman, seen here in a scuba event at the 2006 National Disabled Veterans Winter Sports Clinic, lost a leg in 2002 in a motor vehicle accident while on active duty. He is a certified peer counselor with the Amputee Coalition of America.

prostheses, but they are still hopeful the next generation of prostheses is going to make things even better. They want the opportunity to try future models that may improve function and quality of life.

The survey shows that OEF/OIF Veterans tend to go through far more prostheses than did their Vietnam counterparts in their initial post-injury period. Why is that? In terms of upper-limb loss, almost every participant from OEF/OIF has set aside at least one myoelectric or advanced limb. It's not meeting their needs. They go back to a more old-fashioned body-powered device for many activities. So we perhaps need to be more careful about what we're initially providing and assess whether it's really the best limb to meet the person's

needs. Also, we've seen that the newer limbs are different from those prescribed in the post-Vietnam era. They are more flexible and compliant but less durable than the older laminated materials; thus, they have to be replaced faster. In addition, there are much higher functional demands for the OEF/OIF veterans than for the Vietnam guys. In fact, about 20 percent have returned to active duty after losing a limb. That's not to say, though, that there aren't Vietnam Veterans who are really active. I had to call one guy to confirm there was no mistake in his data: that he had gone through 40 upper-limb prostheses. True to his word, he's just very active. He runs a farm, and he helps kids with ski school, and he had just broken a prosthesis the week

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sites, referred to as “demonstration labs,” will “provide a sophisticated, robust platform for critical evaluation of the patient-centered medical home.”

Atkins adds that VA is “setting a great example of forward thinking” by building research into the process from an early stage. “Too often, health systems decide to do something new without investing in making sure they do it the most effective and efficient way, and in learning how to do it even better.”

The medical home concept has been studied outside VA, mainly in small pilot projects, by systems such as Kaiser Permanente and Group Health Cooperative. But no prior research has been on the scale of VA’s new initiative. So outside experts—many of whom talked with VA to help the agency plan its implementation—are now eager to learn from VA’s nationwide experiment.

“They’re all keen to see our results,” says Stephan Fihn, MD, MPH, who co-chaired the committee that developed the research program and is now heading a coordinating center overseeing the five independent labs. “Can a system with more than 1,000 care sites do this? There’s great heterogeneity in our system. How do you retain the flexibility to adapt the patient-centered medical home to settings as diverse as a small rural clinic and a large, academically affiliated primary care clinic that’s got 150 providers and medical residents?”

Many elements of medical home already in place in VA

Fihn says many ideal elements of the medical home are already facts on the ground in VA—such as greater roles for non-physician providers and team-based

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models of care. “We were one of the first to enthusiastically embrace nurse practitioners,” says the Seattle-based physician-researcher. “I’ve worked side by side with nurse practitioners in the clinic since 1982.” Other examples include electronic health records and telemedicine.

The challenge now, says Fihn, is blending the pieces into a cohesive, integrated whole. “We’ve known some of the pieces, but no one’s understood how to assemble the whole. The demonstration labs are evaluating which pieces matter most. How are they best constructed? What are the effects of variations in that construction? How should they vary according to types of

patients and practice settings? How do we ensure that coordination occurs?”

The research effort will benefit because so many pieces of the medical home puzzle are already in place in VA, says Rachel Werner, MD, PhD, of the Philadelphia VA Medical Center and VA’s Center for Health Equity Research and Promotion, who is lead investigator for one of the five demo labs.

“It frees us up to go a step further and think about what we can do to make the care more patient-centered and more team-based,” she says. “We can move beyond the structural elements—information technology, electronic health records, performance measurement—and work on the culture of care.”

An expanded version of this article can be found on the VA Research website at www.research.va.gov, in the features section. 

Hallmarks of the patient-centered medical home

Gordon Schectman, MD, acting chief consultant for VA’s Office of Patient Care Services, provides the following definition of the patient-centered medical home (PCMH) on an Intranet forum for VA staff involved in implementing the model: “A patient-centered medical home is a team-based model of care led by a personal provider who enables continuous and coordinated care through a patient’s lifetime to maximize health outcomes. The PCMH practice is responsible for providing for all of a patient’s health care needs or appropriately coordinating care with other qualified professionals.”

Other sources describe the ideal PCMH as one in which clinicians:

- take personal responsibility for patients’ care
- offer expanded hours and availability on short notice
- have email and phone contact with patients to augment visits
- use the latest technology, including electronic health records
- provide regular check-ups and offer preventive care based on patients’ individual risk factors
- help patients make healthy lifestyle decisions
- offer patients the latest evidence-based treatments
- coordinate care with other providers when needed and ensure that all procedures are relevant and necessary

Study finds little hard evidence for lifestyle steps to keep brain sharp, but suggests further research

Eating right, exercising, doing mental activities—these and other steps have long been recommended to stave off the mental decline that often comes with age and can foreshadow Alzheimer’s disease. But while these habits may be good for overall health, there is little hard evidence of their ability to keep the mind sharp, says a study by a team with VA and Duke University. The surprising results appeared online June 14 in the *Annals of Internal Medicine*.

The researchers reviewed the existing scientific evidence on factors ranging from diet, disease and toxic exposures to genetics and social interaction. “Few [factors] had sufficient evidence from which to draw firm conclusions about their association with cognitive decline,” wrote the study team, which included physician-researchers John W. Williams, MD, and Tracey Holsinger, MD, of the Durham (N.C.) VA Medical Center.

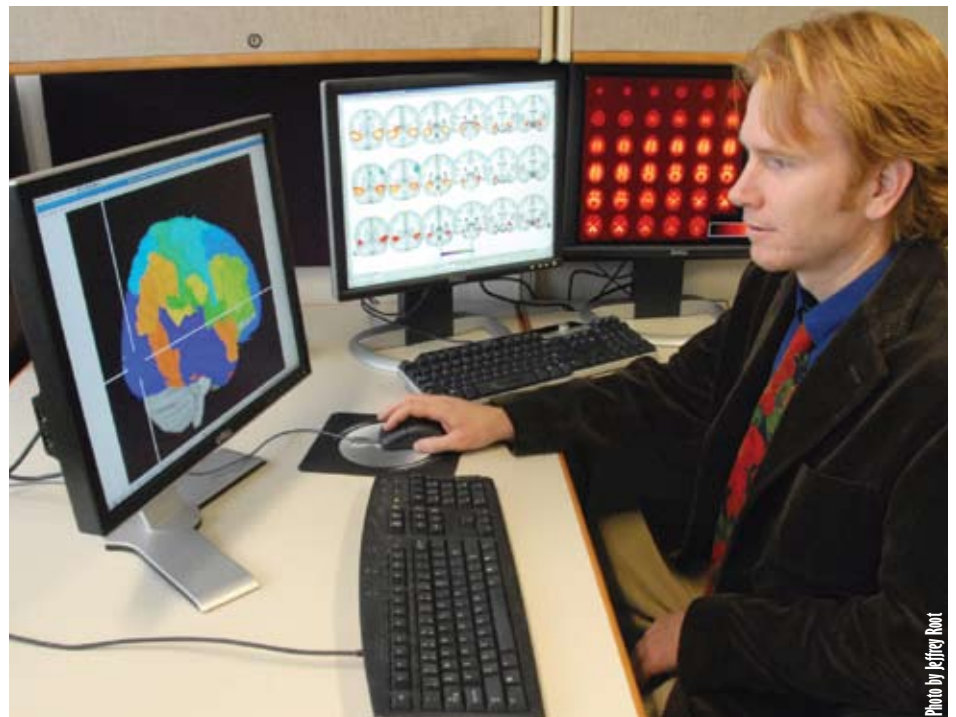
The study did find, however, that habits such as physical exercise and a Mediterranean diet—rich in fish, fruits and vegetables—could “probably” be credited with helping to lower the risk of mental decline. And one randomized trial, for example, showed modest benefits from mental training in specific areas such as memory or reasoning.

Factors that were linked in varying degrees to a *higher* risk of mental decline were tobacco use, the ApoE4 genetic variation, diabetes, metabolic syndrome, and depression.

The authors concluded that the “current literature does not provide adequate evidence to make recommendations for interventions” to slow or prevent cognitive

decline. But they did suggest that further research on Alzheimer’s prevention should focus on areas such as cognitive training, physical exercise and healthy diet.

The review study was conducted as part of an expert panel funded by the Agency for Healthcare Research and Quality and the National Institutes of Health. —



Dr. Sterling Johnson’s team, with VA and the University of Wisconsin, found reduced gray matter in Alzheimer’s-susceptible brain regions in healthy adults with certain genetic variations.

VA research featured at Alzheimer’s meeting

Several studies involving VA investigators were featured in a July 14 news briefing at the International Conference on Alzheimer’s Disease, held in Hawaii. Two studies by a team with the University of Wisconsin and the Geriatric Education, Research and Clinical Center (GRECC) at the Madison VA Medical Center yielded key insights on a recently identified Alzheimer’s risk gene called TOMM40. One study, which included 726 healthy middle-aged men and women with a family history of the disease, found that those with a high-risk version of the gene did worse on memory tests. A related study found that healthy adults with the high-risk version of TOMM40—along with a certain variant of another gene—had reduced volume in two brain regions affected early in Alzheimer’s. In a separate study at the VA Puget Sound Health Care System, GRECC researchers treated 109 people affected by Alzheimer’s or mild cognitive impairment with either placebo or a nasal spray containing insulin. Those who got insulin performed better on some mental tests but not others. In those who showed benefits, there were also positive changes in Alzheimer’s biomarkers in spinal fluid. —

Inside: Probing the patient-centered medical home

SURVEY *(from page 5)*

before while he was towing someone on a ski rope with his arm.

What else can VA do to optimize how it prescribes prostheses? The mindset in the past was, you got one prescription and that was it. In fact, sometimes it was a choice between a wheelchair and a prosthetic leg, but not both. What we now know is that there can and should be a mix and match of different prostheses for the different functions a person is performing. If a guy wants to get up on his roof and replace shingles, he needs one kind of an arm to do that. If he wants to engage in recreation, he may need a different arm. We've got to individualize the prescriptions based on individual need. Likewise, we can't generalize based on age. There are some Vietnam Veterans who are deciding they want the opportunity to try current prostheses, and some OEF/OIF Veterans who want to get on with life and not spend quite so much time every day dealing with their prostheses. So it crosses both ways. Some people want to simplify, and others want to try new devices. The bottom line is individualizing Veterans' care to meet their needs and goals. —

HIGHLIGHTS



Enabling limb control—Capt. Nelson P. Jackson (USN-Ret.) wears 3D glasses and uses a “space mouse” to control a virtual arm on screen at the recent 5th Annual Capitol Hill Modeling and Simulation Expo. The virtual environment was designed by bioengineers at the Cleveland FES Center, a VA research center of excellence, to help teach people with paralysis how to control their disabled arm when it is activated through electrical stimulation. Working with study volunteers, the engineers are refining control algorithms that will eventually be part of implantable FES (functional electrical stimulation) systems. Related work at the center may figure into control systems for prosthetic arms. “Our patients don’t use the space mouse,” explained FES Center investigator A. Bolu Ajiboye, PhD. “The goal of the virtual environment is to help them adapt to whatever control mechanism is in place.” At the Capitol Hill event, the FES Center team showed a video illustrating a potential application: A spinal-cord-injured research participant was able to control a virtual arm through her brain signals, as captured by implanted electrodes. That phase of the research is taking place in partnership with VA’s Center for Restorative and Regenerative Medicine. —