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VA HEALTH CARE

Observations on Medical Care Provided to Persian Gulf Veterans

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VA Health Care: Observations on Medical Care Provided to Persian Gulf Veterans

Mr. Chairman and Members of the Subcommittee:

We are pleased to be here today to discuss our ongoing evaluation of the medical care the Department of Veterans Affairs (VA) provides to veterans who are suffering from illnesses they attribute to their military service during the Persian Gulf War.

Persian Gulf veterans have reported an array of symptoms including fatigue, skin rashes, headaches, muscle and joint pain, memory loss, shortness of breath, sleep disturbances, gastrointestinal conditions, and chest pain. VA's program to serve Persian Gulf veterans is a four-pronged approach addressing medical care, research, compensation, and outreach and education. The medical care portion includes a medical examination,[1] inpatient and outpatient treatment, specialized evaluations at four referral centers, and readjustment and sexual trauma counseling. More than 65,000 Persian Gulf veterans have completed the medical examination, or "registry exam."

My comments this morning will focus on information we have gathered to date, at your request, on (1) veterans' satisfaction with VA care and (2) the extent to which veterans are diagnosed, counseled, treated, and monitored. We will also discuss a model of care at one medical center that Persian Gulf veterans seem to find more responsive to their needs.

Our information is based on observations and opinions from officials at VA headquarters; VA's Atlanta Veterans Integrated Service Network office; medical centers in Washington, D.C., Atlanta, and Birmingham; referral centers in Washington and Birmingham; and veterans service organizations; and from dozens of Persian Gulf veterans, both individually and in group interviews. We also reviewed a sample of medical records for 20 veterans who had received the registry exam in two of the three medical centers we visited to evaluate the registry exam process. We did not attempt to determine whether the tests, evaluations, and treatment provided to these veterans were appropriate but rather the extent to which VA followed its guidelines for evaluation and treatment and whether Persian Gulf veterans were satisfied with the treatment received. While the scope of our work to date is not broad enough to generalize to conditions throughout VA, we believe that, along with previous studies of these issues, our work does serve as an indicator of the medical care that Persian Gulf veterans receive.

[1]The Persian Gulf Registry Exam consists of a medical history, physical examination, and laboratory tests. The results of the examination are entered into a database that contains information on all Persian Gulf veterans who have received the examination.

The Persian Gulf veterans that we have talked with and who wrote to us, along with veterans we heard about through veterans service organizations, appeared to be confused by, frustrated with, and mistrustful of VA and the care they received for their illnesses. While veterans appreciated the efforts of some individual VA staff, they expressed dismay with the "system," which often extends beyond VA to other agencies and, for some, to the federal government in general. Specifically, veterans continued to cite delays in receiving services, the nonsympathetic attitudes of some health care providers, the sometimes cursory nature of the registry exam, poor feedback and communication with health care personnel, and a lack of postexamination treatment.

On the basis of our work to date, it does not appear that VA's guidance regarding the evaluation and treatment of Persian Gulf veterans is being consistently implemented in the field. We observed, for example, that some physicians did not perform all of the symptom-specific tests recommended by VA's Uniform Case Assessment Protocol, which could result in some veterans not receiving a clearly defined diagnosis for their symptoms. We also found that personal counseling of veterans seldom occurred. In addition, the form letters sent to veterans at the completion of the registry exam did not always sufficiently explain the test results or diagnosis, which leaves veterans frustrated. Physicians' views were mixed regarding the origin of the symptoms experienced by Persian Gulf veterans. We heard and read physician comments indicating that they believe Persian Gulf veterans' problems are only "in their heads." However, other physicians displayed open attitudes about treating the veterans' symptoms and determining the origin of their illnesses.

Medical center personnel cited limited resources and increased workloads as reasons their efforts are not as timely and responsive as they and veterans would like. One medical center we visited had experienced delays of up to 6 months in scheduling registry exams. However, steps are being taken at certain VA facilities to improve service. For example, at one medical center we visited, veterans now have the option of receiving treatment in a Persian Gulf Special Program Clinic. The Clinic allows veterans to receive primary care from medical staff experienced with Gulf War veterans and their concerns and has established a focal point for providing clinical management of Persian Gulf veterans' care.

Persian Gulf Veterans' Expectations Remain Unfulfilled

The Persian Gulf veterans we spoke with held several common expectations regarding VA health care. They expected to be scheduled for the registry exam and tested in a timely manner. They expected doctors to listen to their symptoms and to take the problems they experienced seriously by performing the necessary tests and evaluations in order to reach a diagnosis. The veterans expected to be told their test results and to receive counseling and consultation regarding the need for further testing or treatment.

Veterans' perceptions of what is provided, however, were considerably different. Some veterans said they experienced delays in receiving the registry exam and follow-up testing they requested. Once scheduled for care, veterans said that some VA doctors and health care professionals projected the attitude that the symptoms Persian Gulf veterans experience are "all in their heads." Some veterans commented that the exam they received seemed too superficial to fully evaluate the complex symptoms they were experiencing.

Veterans indicated that personal counseling is generally not provided on the results of the registry exam and that this is true for veterans with diagnoses as well as for those without. The form letter sent to veterans at the completion of the exam generated considerable anger among Persian Gulf veterans we talked with, who interpreted it to mean that since their test results came back normal, the VA physician believed there was nothing wrong with them. Even some veterans who received a diagnosis did not understand their diagnosis or believe that their treatment was effective. For example, several veterans believed their medications made them feel worse and discontinued them on their own.

Extent of Services Provided to Persian Gulf Veterans

Many Persian Gulf veterans have received care from VA for what they believe are service-related illnesses. These illnesses are manifested in a wide range of symptoms in multiple diagnostic categories. Although VA has developed comprehensive guidance for physicians to use in diagnosing Persian Gulf veterans, it appears to be inconsistently followed.

Medical Services Provided to Persian Gulf Veterans

The medical care portion of VA's approach is provided in a variety of settings. Of the total 697,000 veterans who served in the Persian Gulf War, more than 65,000 have completed the registry exam, which is available in most of VA's 159 medical centers. More than 191,000 veterans have been seen in VA's outpatient care clinics; about 19,000 veterans have been

admitted to inpatient care in VA medical centers. Approximately 390 veterans have received special evaluations in referral centers in Washington, D.C., Birmingham, Houston, and Los Angeles; and more than 79,000 have received readjustment counseling at VA's Vet Centers.[2]

The diagnoses recorded in the registry exam database for Persian Gulf veterans spanned a range of illnesses and diagnostic categories. About 25 percent of registry diagnoses were for musculoskeletal and connective tissue disorders, approximately 15 percent for respiratory problems, 12 percent for gastrointestinal conditions, 14 percent for skin disorders, 16 percent for psychiatric conditions, 7 percent for cardiovascular and circulatory problems, 7 percent for infectious diseases, and 5 percent for injury and poisoning. Twenty-six percent of registry participants did not have a definitive medical diagnosis, and 12 percent reported no health problem.[3] The latter group asked to participate in the examination because they were concerned that their future health might be affected as a consequence of their service in the Gulf War.

Evaluation and Treatment of Persian Gulf Veterans Do Not Appear to Consistently Follow Guidelines

In 1995, VA implemented a Uniform Case Assessment Protocol designed in conjunction with the Department of Defense and the National Institutes of Health to provide guidance to the physicians responsible for administering the Persian Gulf Registry Exam. The protocol consists of two phases. Phase I requires registry physicians to (1) obtain a detailed medical history, which includes collecting information on exposure to environmental and biochemical hazards; (2) conduct a physical examination; and (3) order basic laboratory tests. Phase II, which is to be undertaken if veterans still have symptoms that are undiagnosed after phase I, includes additional laboratory tests, medical consultations, and symptom-specific tests. Veterans who do not receive a diagnosis after phase II may be sent to one of VA's four referral centers for additional testing and evaluation. At the completion of these examinations, veterans are to receive personal counseling about their test results. Once diagnosed, veterans are generally referred to primary care teams for treatment. VA has issued a contract to the Institute of Medicine to review the appropriateness of its Uniform Case Assessment Protocol. The Institute's findings are due by the end of 1997.

[2]These numbers represent individual veterans provided service in each setting. The same veteran could be counted more than once if he or she was seen in more than one setting. Also, for outpatient visits, VA's data do not indicate whether the veterans were seen for Persian Gulf-related illnesses.

[3]Percentages total more than 100 percent because some veterans have multiple diagnoses.

Presently, the protocol remains VA physicians' primary reference on how to evaluate Persian Gulf veterans' conditions and to obtain an accurate diagnosis of the symptoms they report. According to VA's guidance, the veterans registry physician or designee is responsible for clinical management of veterans on the registry and serves as their primary health care provider unless another physician has been assigned this responsibility. According to VA program guidance, the registry physician's essential responsibilities include counseling the veteran as to the purpose of the examination, conducting and documenting the physical examination, and personally discussing with each veteran the examination results and need for additional care. The registry physician is also to prepare and sign a follow-up letter explaining the results of the registry examination and may initiate, if necessary, the patient's further evaluation at one of VA's referral centers.

On the basis of our review of medical records and discussions with program officials, including physicians, it does not appear that VA's guidance is being consistently implemented in the field. For example, while the protocol mandates that veterans without a clearly defined diagnosis are to receive additional baseline laboratory tests and consultations, not all such veterans received the full battery of diagnostic procedures. In some cases, physicians appeared to stop following the protocol even though a clearly defined diagnosis had not been reached. In addition, several of the records we reviewed indicated that the physician's diagnosis was simply a restatement of the veteran's symptoms. For example, a veteran who complained of major joint stiffness and sleep disturbances was diagnosed as having major joint stiffness and sleep disturbances. Furthermore, veterans suffering from undiagnosed illnesses were rarely evaluated at VA's referral centers; of the approximately 15,000 cases that VA reported as having undiagnosable illnesses, only 390 veterans had been evaluated at a referral center. While VA has a quality assurance mechanism for evaluating the care provided by its medical centers, that mechanism neither ensures continuity of care for Persian Gulf veterans nor provides for follow-up with veterans who need continued care. As a result, veterans are often confused about the status of their ongoing treatment.

At two locations we visited, the registry physician was rarely involved in the phase I examination process, instead delegating this task to a physician's assistant or nurse. In several cases, medical records indicated that the registry physician did not even review the results of the examination. After the phase I examination, instead of receiving ongoing

treatment managed by the registry physician, veterans were referred to one of the medical center's primary care teams for postexamination treatment. Here, Persian Gulf veterans are seen by other doctors who treat all veterans and do not concentrate on the specific needs of Persian Gulf veterans. Veterans who expect treatment designed for those suffering from Gulf War illnesses appeared more likely to express frustration and disappointment with the care they received.

According to VA guidance, counseling the veteran about the examination results is one of the key responsibilities of the registry physician. However, our work to date suggests that personal counseling between veterans and their physicians rarely takes place. Registry medical staff, as well as veterans we talked with, stated that feedback on examination results is typically provided through a form letter to veterans. The letter generally states the results of laboratory tests and provides a diagnosis if one was reached. In some instances, when laboratory results were negative, the veteran perceived that VA does not believe there is a problem. Even when a diagnosis is reached, the letter does not explain the meaning of complex or uncommon medical terms.

We discussed these concerns with registry and other physicians as well as VA Persian Gulf program officials. Several of the physicians we interviewed believed they should have the flexibility to use their own clinical judgment in determining which tests are necessary to establish a diagnosis and treatment plan. One physician stated that a good physician should, in most cases, be able to diagnose a veteran's symptoms without using the more complex battery of tests mandated by the protocol. We were told that some of the phase II symptom-specific tests are invasive procedures that could have serious side effects, and unless the tests are specifically needed, they should not be given routinely just because a veteran has symptoms. Other physicians resisted prescribing some phase II tests because of the associated costs. Furthermore, some physicians told us that they believed there was no physical basis for the symptoms Persian Gulf veterans were experiencing and that these symptoms were often psychologically based and not very serious. This attitude may contribute to physicians' lack of enthusiasm for the protocol exams.

We also noted that VA has established no mechanism to monitor treatment outcomes for Persian Gulf veterans. The VA official responsible for the Persian Gulf program told us that if monitoring of treatment outcomes does occur, it will be initiated in primary care.

Medical Centers' Efforts to Improve Care for Persian Gulf Veterans

Medical center personnel often cited limited resources and increased workloads as reasons their efforts were not as timely and responsive as they and veterans would like. Some facilities are taking steps to overcome the negative experiences of Persian Gulf veterans. For example, one of the three medical centers we visited uses a different model to provide care to these veterans. At this facility, veterans have the option of receiving treatment in a Persian Gulf Special Program Clinic. Although it operates only on Tuesdays and Fridays, the Clinic allows veterans to receive primary care from medical staff experienced with Gulf War veterans and their concerns. Veterans are still referred to hospital specialists as necessary but, unlike the other two facilities we visited, responsibility for monitoring patients' overall medical treatment is assigned to the Clinic's case manager. The case manager is a registered nurse who serves as an advocate for veterans and facilitates communications between patients, their families, and the medical staff. The specific steps that are to be used in monitoring patient care had not been developed at the time of our visit. The Clinic staff also interacts regularly with the Persian Gulf Advisory Board, a local group of Persian Gulf veterans who meet weekly in the VA medical center to discuss specific concerns.

Veterans we spoke with were pleased with the Clinic and supported its continued operation. They believed that it reflects a VA commitment to take seriously the health complaints of Gulf War veterans. They also believed that the Clinic gives veterans access to physicians who are sympathetic and understand the special needs of Persian Gulf veterans and their families. In addition, veterans we talked with who use this facility indicated a higher level of satisfaction with the care they received than the veterans who use the two other medical centers.

Mr. Chairman, this concludes my prepared statement. We will continue to assess these issues and will report our findings and conclusions at a later date. I will be happy to answer any questions you or other members of the Subcommittee may have.

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