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April 20, 1998

The Honorable Arlen Specter
Chairman
The Honorable John D. Rockefeller IV
Ranking Minority Member
Committee on Veterans' Affairs
United States Senate

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

Almost 700,000 members of the U.S. military served during the Persian Gulf War. Some of these veterans have reported an array of symptoms that they attribute to their service in the Gulf War, including fatigue, skin rashes, headaches, muscle and joint pain, memory loss, shortness of breath, sleep disturbances, gastrointestinal conditions, and chest pain. The absence of data on the health status of service members who served in the Gulf War–including both baseline information and postdeployment status information–has greatly complicated the epidemiological research on the causes of Gulf War illnesses.[1]

In 1992, the Department of Veterans Affairs (VA) established the Persian Gulf Registry Health Examination Program to act as a health screening database, as well as to assist Gulf War veterans in gaining entry into a continuum of VA health care services by providing them with a free initial physical examination. In 1995, VA modified the registry program by implementing the Uniform Case Assessment Protocol, a standardized approach for conducting examinations that was designed in conjunction with the Department of Defense and the National Institutes of Health. The protocol provides further guidance to the physicians responsible for diagnosing Persian Gulf veterans. According to VA's Under Secretary for Health, the registry's record of symptoms, diagnoses, and exposures also makes it valuable for health surveillance purposes. VA required

[1]Defense Health Care: Medical Surveillance Improved Since Gulf War, but Mixed Results in Bosnia (GAO/NSIAD-97-136, May 13, 1997).

160303

its 160 medical facilities that have a Persian Gulf program to designate a registry physician to be responsible for implementation. By November 1997, almost 67,000 Persian Gulf veterans had participated in VA's registry program.

We are nearing the completion of a review of the Persian Gulf registry program to determine whether VA is following the processes it established for providing health care to Gulf War veterans. This review was requested by the House Committee on Veterans' Affairs, Subcommittee on Health, and a final report is scheduled to be issued in the summer of 1998. Your staff requested that we provide a written summary of the preliminary results of our work in order to assist in your Committee's review of Persian Gulf issues, and the House Subcommittee was agreeable to the release of this information. We are also enclosing a list of recent GAO products addressing various Gulf War issues.

During our review work, we evaluated VA's diagnosis, counseling, treatment, and monitoring of Persian Gulf veterans; met with VA officials responsible for managing the registry program; and reviewed legislation, program guidance, operating procedures, and management reports. We also visited VA medical facilities in Washington, D.C.; Atlanta, Georgia; Birmingham, Alabama; Manchester, New Hampshire; El Paso, Texas; and Albuquerque, New Mexico, as well as VA referral centers in Washington and Birmingham, to talk with program staff members, observe program operations, and review a sample of veterans' medical records to identify the types of program services provided. Further, we had personal contact with over 150 Persian Gulf veterans to discuss their level of satisfaction with VA's health care services. We did not attempt to determine the appropriateness of the tests, evaluations, and treatment provided to these veterans, but rather whether VA followed its guidelines and procedures in caring for Persian Gulf War veterans. Our work, which began in March 1997, has been performed in accordance with generally accepted government auditing standards.

In summary, we have found that VA has not fully implemented an integrated diagnostic and treatment program to meet the health care needs of Persian Gulf veterans. For example, while VA has developed a registry protocol to guide the evaluation and diagnosis of Persian Gulf veterans, the protocol is not being consistently implemented in the field. Moreover, although VA recognizes that using coordinated case management techniques will improve both treatment effectiveness and patient satisfaction, this approach has not been implemented at four of the six facilities we visited. Persian Gulf veterans whose health care is coordinated by physicians who specialize in Persian Gulf illnesses appeared much more satisfied with their care than their counterparts

who did not receive this continuity of care. Having registry physicians or specific providers dedicated to the diagnosis and treatment of Persian Gulf veterans may also yield other benefits, such as increasing the likelihood of recognizing symptomatic and diagnostic trends; identifying appropriate and effective treatment options; and, possibly, learning more about the nature and origin of Persian Gulf illnesses.

REGISTRY EXAMINATION PROTOCOL IS INCONSISTENTLY APPLIED

VA's protocol for conducting registry examinations consists of two phases. Phase I requires registry physicians to obtain a detailed medical history from the veteran, which includes collecting information on exposures to environmental and biochemical hazards; conduct a physical examination; and order basic laboratory tests. Phase II, which is to be undertaken if a veteran still has symptoms that are undiagnosed after phase I, involves supplemental laboratory tests, symptom-specific tests, medical consultations, and other 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.

The protocol continues to be VA physicians' primary reference on how to evaluate the condition of Persian Gulf veterans and obtain an accurate diagnosis of the symptoms they report. According to guidance issued by VA, the 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. The registry physician's essential responsibilities also include counseling the veteran about the purpose of the examination; conducting and documenting the physical examination; personally discussing with each veteran the examination results and whether additional care is needed; preparing and signing a follow-up letter explaining the results of the registry examination; and initiating, if necessary, the patient's further evaluation at one of VA's referral centers.

In March 1998, the Institute of Medicine (IOM), an organization of the National Academy of Sciences, published a report evaluating the adequacy of VA's Persian Gulf registry program.[2] In addition to other observations, the IOM

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[2]Institute of Medicine, Adequacy of the VA Persian Gulf Registry and Uniform Case Assessment Protocol (Washington, D.C.: National Academy Press, 1998).

report states that deviations in protocol implementation introduced inconsistencies in clinical evaluation across VA facilities.

Similarly, the preliminary results of our review of medical records and discussions with program officials indicate that VA's guidance is not being consistently implemented in the field. For example, at four of the six facilities we visited, veterans' medical histories were very brief and generally did not address all of their environmental exposures during the Gulf War. In addition, at two of the six facilities we visited, physicians' assistants or nurse practitioners conducted the phase I examination, and registry physicians often did not review the results of the examination, as required by the registry protocol. Moreover, while the protocol mandates that veterans without a clearly defined diagnosis receive laboratory tests and consultations, not all such veterans received the battery of required diagnostic procedures. Our review of 110 veterans' medical records indicated that in 40 cases veterans received no, or minimal, symptom-specific testing for unresolved complaints or undiagnosed symptoms.

VA's guidelines also require breast and pelvic examinations for female veterans. Of the 13 female Persian Gulf veterans whose medical records we reviewed, only 8 received these examinations. Several of the records we reviewed indicated that the physician's diagnosis was simply a restatement of the veteran's symptoms. Furthermore, veterans suffering from undiagnosed illnesses were rarely evaluated at VA's referral centers. Of the approximately 16,000 veterans[3] that VA reported as having no medical diagnosis, only about 500 had been evaluated at a referral center. While VA central office officials told us that some medical centers are now capable of conducting more detailed tests, we found that in one full-service medical center we visited, 14 of the 20 cases we reviewed received no diagnosis and very little detailed testing was provided. Veterans we spoke with were often frustrated with the diagnostic process.

According to VA guidance, counseling the veteran about the examination results is one of the key responsibilities of the registry physician. However, we found that physicians often do not personally counsel veterans. For example,

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[3]Analysis of the Persian Gulf registry data performed by VA's Office of Public Health and Environmental Hazards shows that the number of veterans who received no medical diagnosis ranges from about 21 to 26 percent of those receiving the examination, depending on when the examination was given.

in only one of the six facilities we visited did medical records document that counseling took place. Veterans we spoke with indicated that personal counseling is generally not provided on the results of the registry exam, and this is true for veterans who received a diagnosis as well as for those who did not. VA medical staff, as well as veterans we talked with, stated that feedback on examination results is typically provided through a form letter. The letter generally states the results of laboratory tests and provides a diagnosis if one was reached. Some form letters sent to veterans at the completion of the exam generated considerable anger among Persian Gulf veterans, who interpreted the letters to mean that, since their test results came back normal, the physicians believed either that there was nothing medically wrong with them or that their condition was not related to service in the Gulf. The following is an example of the wording used in a letter one facility sent to a 26-year-old veteran who had complained of chronic diarrhea since 1991, anxiety attacks since 1992, shortness of breath beginning in 1993, and chronic vomiting since 1995. The letter stated, "at the present time there is no evidence that Persian Gulf duty is causing any hidden health problems." At this same facility, we were told that counseling letters were sent to veterans without incorporating the results of all their diagnostic tests.

We discussed these concerns with registry and other physicians as well as with 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 a treatment plan. One physician stated that a good physician should be able, in most cases, to diagnose a veteran's symptoms without using the 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 that, 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 believe there is no physical basis for the symptoms Persian Gulf veterans are experiencing and that these symptoms are often psychologically based and not very serious.

In addition, physicians at two facilities we visited told us they were experiencing difficulty setting up consults and tests that were available only through other VA facilities. They stated that this difficulty often resulted in increased travel for the Persian Gulf veterans, delays in scheduling appointments, and increased waiting times to receive consult and test results.

PERSIAN GULF VETERANS PREFER CONTINUOUS COORDINATED CARE

VA's Persian Gulf program guidance assigns the registry physician responsibility for providing continuous care to veterans experiencing multiple symptoms and for serving as their primary health care provider unless another physician has been assigned. VA's Under Secretary of Health has indicated that using case management techniques to coordinate health care services for Gulf War veterans with complex medical conditions would improve both treatment effectiveness and patient satisfaction.

At only two of the six facilities we visited did we observe Persian Gulf veterans receiving continuous coordinated care, either from the registry physician or from a clinical staff member serving this special population group. For example, at the first 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 responsibility for coordinating and monitoring patients' overall medical care is assigned to the Persian Gulf clinic's case manager, who is supervised by the Persian Gulf registry physician. The case manager is a registered nurse who serves as an advocate for veterans and facilitates communication among patients, their families, and the medical staff. The clinic staff also interact regularly with the Persian Gulf Advisory Board, a local group of Persian Gulf veterans who meet weekly at the VA medical center to discuss specific concerns. Veterans we spoke with were pleased with the clinic and supported its continued operation. They believe the existence of the clinic reflects a VA commitment to take seriously the health complaints of Gulf War veterans. They also believe that the clinic gives veterans access to physicians who are sympathetic and who understand the special needs of Persian Gulf veterans and their families. In addition, veterans we talked with who use this facility indicated a high level of satisfaction with the care they receive.

At a second facility, the registry physician serves as the primary care physician for all Persian Gulf veterans requiring ongoing treatment for their Gulf-related ailments. This physician acts as the veterans' case manager, coordinating all necessary consults, scheduling follow-up visits, and monitoring the clinical progress of Persian Gulf patients. Veterans at this facility have a clear point of contact whenever they have questions or concerns about their treatment. Veterans we spoke with told us they were very satisfied with the treatment

they receive and were extremely complimentary about the care and concern shown by the registry physician.

At the other four facilities we visited, however, there appeared to be little or no coordination between the registry examination process and the veterans' ongoing treatment. In effect, these veterans were mixed in with the general hospital population and received no follow-up treatment from physicians familiar with Gulf War illnesses. Some of the veterans we spoke with who were treated at these four facilities told us that they felt that their treatment was ineffective. In fact, several veterans said their medications made them feel worse and discontinued using them. Physicians we spoke with acknowledged that greater continuity between the diagnostic and treatment process would benefit both the physician and the veteran.

On the basis of our preliminary work, we believe that greater continuity and coordination between the diagnosis and treatment of Persian Gulf veterans offers several advantages.

- It validates veteran concerns. By having physicians clearly identified as responsible for the care and treatment of Persian Gulf veterans, the veterans are more confident that VA takes their complaints seriously.

- It enhances the chances veterans will receive follow-up care. After completing the registry examination, veterans have an immediate point-of-contact should they have questions about their condition or require follow-up care.

- It fosters increased awareness of VA's referral centers. One of the primary care doctors we spoke with was unaware of the availability of VA referral centers for veterans with undiagnosed conditions or those who do not respond to treatment. If designated physicians were responsible for treatment of Persian Gulf veterans, awareness and use of the referral centers would probably increase.

- It allows for a better treatment focus. If designated physicians care for Persian Gulf veterans, the likelihood of recognizing symptomatic and diagnostic patterns and developing an effective treatment program is increased. This approach may also lead to greater understanding of the nature and origin of Persian Gulf illnesses.

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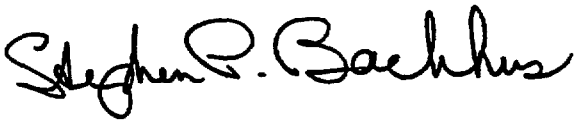
We are sending copies of this correspondence to the Secretary of Veterans Affairs and will make copies available to others on request.

Major contributors to this correspondence included George Poindexter, Stuart Fleishman, Patricia Jones, Jon Chasson, and Steve Morris. Please contact me on (202) 512-7101 if you have any questions.



Stephen P. Backhus
Director, Veterans' Affairs and
Military Health Care Issues

RELATED GAO PRODUCTS

Gulf War Veterans: Incidence of Tumors Cannot Be Reliably Determined From Available Data (GAO/NSIAD-98-89, Mar. 3, 1998).

Gulf War Illnesses: Federal Research Strategy Needs Reexamination (GAO/T-NSIAD-98-104, Feb. 24, 1998).

Gulf War Illnesses: Research, Clinical Monitoring, and Medical Surveillance (GAO/T-NSIAD-98-88, Feb. 5, 1998).

Gulf War Illnesses: Public and Private Efforts Related to Exposures of U.S. Personnel to Chemical Agents (GAO/NSIAD-98-27, Oct. 15, 1997).

Gulf War Illnesses: Reexamination of Research Emphasis and Improved Monitoring of Clinical Progress Needed (GAO/T-NSIAD-97-191, June 25, 1997).

Gulf War Illnesses: Enhanced Monitoring of Clinical Progress and of Research Priorities Needed (GAO/T-NSIAD-97-190, June 24, 1997).

Gulf War Illnesses: Improved Monitoring of Clinical Progress and Reexamination of Research Emphasis Are Needed (GAO/NSIAD-97-163, June 23, 1997).

VA Health Care: Observations on Medical Care Provided to Persian Gulf Veterans (GAO/T-HEHS-97-158, June 19, 1997).

Defense Health Care: Medical Surveillance Improved Since Gulf War, but Mixed Results in Bosnia (GAO/NSIAD-97-136, May 13, 1997).

Operation Desert Storm: Health Concerns of Selected Indiana Persian Gulf War Veterans (GAO/HEHS-95-102, May 16, 1995).

Operation Desert Storm: Questions Remain on Possible Exposure to Reproductive Toxicants (GAO/PEMD-94-30, Aug. 5, 1994).

Operation Desert Storm: Potential for Reproductive Dysfunction Is Not Being Adequately Monitored (GAO/T-PEMD-94-31, Aug. 5, 1994).

Operation Desert Storm: Problems With Air Force Medical Readiness (GAO/NSIAD-94-58, Dec. 30, 1993).

Operation Desert Storm: Improvements Required in the Navy's Wartime Medical Care Program (GAO/NSIAD-93-189, July 28, 1993).

Operation Desert Storm: Army Not Adequately Prepared to Deal With Depleted Uranium Contamination (GAO/NSIAD-93-90, Jan. 29, 1993).

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