Managing future Gulf War Syndromes: international lessons and new models of care

Charles C. Engel^{1,2,*}, Kenneth C. Hyams³ and Ken Scott⁴

¹*Department of Psychiatry, School of Medicine, Uniformed Services University of the Health Sciences, 4301 Jones Bridge Road, Bethesda, MD 20814-4799, USA*

²*Deployment Health Clinical Center, Walter Reed Army Medical Center, Building 2, Room 3G01 6900 Georgia Avenue, NW, Washington, DC 20307, USA*

³*Office of Public Health and Environmental Hazards, Department of Veterans Affairs, VA Central Office (13A), 810 Vermont Avenue, NW, Washington, DC 20420, USA*

⁴*Directorate of Medical Policy, Canadian Forces Health Services, 1745 Alta Vista Drive, Ottawa, Ontario K1A 0K6, Canada*

After the 1991 Gulf War, veterans of the conflict from the United States, United Kingdom, Canada, Australia and other nations described chronic idiopathic symptoms that became popularly known as 'Gulf War Syndrome'. Nearly 15 years later, some 250 million dollars in United States medical research has failed to confirm a novel war-related syndrome and controversy over the existence and causes of idiopathic physical symptoms has persisted. Wartime exposures implicated as possible causes of subsequent symptoms include oil well fire smoke, infectious diseases, vaccines, chemical and biological warfare agents, depleted uranium munitions and post-traumatic stress disorder. Recent historical analyses have identified controversial idiopathic symptom syndromes associated with nearly every modern war, suggesting that war typically sets into motion interrelated physical, emotional and fiscal consequences for veterans and for society. We anticipate future controversial war syndromes and maintain that a population-based approach to care can mitigate their impact. This paper delineates essential features of the model, describes its public health and scientific underpinnings and details how several countries are trying to implement it. With troops returning from combat in Afghanistan, Iraq and elsewhere, the model is already getting put to the test.

Keywords: chronic fatigue; Gulf War Syndrome; population surveillance; post-traumatic; military; veterans

1. INTRODUCTION

Less than one week after Iraq's invasion of Kuwait on 2 August 1990, the United States began deploying troops to the Arabian Gulf (Leyden & Akin 1997). On 16 January 1991, a devastating air war was launched against Iraq, followed by a swift and decisive 4 day ground war that freed Kuwait from Iraqi military control. By the end of active hostilities on 28 February 1991, an alliance of some 40 Coalition nations had deployed military forces to the theatre of operations, including approximately 697 000 troops from the USA, 53 000 from Britain, 4500 from Canada and 1700 from Australia.

Despite prolonged exposure to an often austere desert environment, morbidity rates among US troops were lower than in previous major conflicts (Gunby 1991; Lindsay & Dasey 1992). Furthermore, mortality

rates were dramatically lower than was estimated immediately pre-war, with only 147 US troops killed in action (Writer *et al.* 1996). Although deployed troops appeared in good health during the war, within a year of war's end some US Gulf War veterans began presenting with a range of non-specific symptoms of unknown origin (Miscellanea Medica 1992). The most commonly reported symptoms included fatigue, headaches, joint pains, skin rash, shortness of breath, sleep disturbances, difficulty concentrating, depression and forgetfulness (DeFraités *et al.* 1992; Persian Gulf Veterans Coordinating Board 1995). Subsequently, there were reports of British, Canadian and Australian veterans with similarly idiopathic symptoms (Goss Gilroy, Inc & Canadian Department of National Defence 1998; Ikin *et al.* 2004; Lee *et al.* 2002).

In addition to idiopathic symptoms, there have been reports of possible increased rates of various medical and psychological illnesses among Gulf War veterans (Persian Gulf Veterans Coordinating Board 1995). Interest has focused on neurological diseases, various malignant cancers, connective tissue diseases, immunologic abnormalities, post-traumatic stress disorder (PTSD) and somatization (Haley *et al.* 1997a,b; Knoke *et al.* 1998; Sartin 2000; Riddle *et al.* 2003; Bullman *et al.* 2005). There also have been questions about possible increased rates of birth defects among children

* Author for correspondence (cengel@usuhs.mil).

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One contribution of 17 to a Theme Issue 'The health of Gulf War veterans'.

born after the war to both male and female Gulf War veterans (Penman *et al.* 1996).

Owing to concerns about the health of Gulf War veterans, the US Department of Veterans Affairs (VA) and Department of Defense (DoD) and the British and Canadian Ministries of Defence established special clinical evaluation programmes to assess veterans' health problems (Joseph *et al.* 1998; Lee *et al.* 2002). To date over 100 000 veterans have been systematically evaluated in these programmes (Department of Veteran Affairs 2002). These veterans' symptoms have been linked to a variety of both medical and psychological illnesses but initial concerns about a new or novel syndrome were not confirmed (Joseph *et al.* 1998).

An extensive medical research programme was launched in the US, UK, Canada and Australia to investigate Gulf War health questions (Coker *et al.* 1999; The Research Working Group of the Persian Gulf War Veterans Coordinating Board 2001). Over 250 million dollars has been spent for this research effort in the US alone and a search of the MEDLINE database produced over 1300 articles related to 1991 Gulf War health. In epidemiological surveys of diverse populations of Gulf War troops, veterans consistently report higher rates of nearly every symptom and symptom-based illness examined compared to non-deployed control groups (The Iowa Persian Gulf Study Group 1996; Haley *et al.* 1997a,b; Fukuda *et al.* 1998; Unwin *et al.* 1999; Kang *et al.* 2000; Cherry *et al.* 2001). However, large-scale epidemiological studies failed to identify an overall increase in hospitalization rates among Gulf War veterans and no consistent increase in specific diseases except for amyotrophic lateral sclerosis (Gray *et al.* 1996; Knoke & Gray 1998; Horner *et al.* 2003). Also, large epidemiological studies find no increase in the overall rate of birth defects among children born after the war to Gulf War veterans (Cowan *et al.* 1997; Araneta *et al.* 2000). However, research has found indications of increased rates of depression, PTSD and small decreases in health-related quality of life among Gulf War veterans compared to non-deployed military personnel (The Iowa Persian Gulf Study Group 1996; Dlugosz *et al.* 1999; Gray *et al.* 1999; Unwin *et al.* 1999; Stimpson *et al.* 2003; Ikin *et al.* 2004; Gifford *et al.* 2006).

In mortality studies (see Gray & Kang 2006), a comprehensive investigation of the US Gulf War veteran population using independent death certificate records found the mortality rate in this population to be comparable to non-deployed era veterans for the first 7–10 years after the war with Iraq (Kang & Bullman 2001). In addition, compared to the demographically similar civilian community, the mortality rate of Gulf War veterans has been less than one-half the rate observed in the general population during the decade since the war with Iraq (Kang & Bullman 2001). Similar findings were obtained in a mortality study of British Gulf War veterans (Ministry of Defense, United Kingdom Defence Analytical Services Agency for UK Defence Statistics 2005).

A series of over one dozen expert panels in the US have evaluated available clinical and research data on Gulf War health issues, but have not confirmed a

unique war-related syndrome (Department of Defense 1994; National Institutes of Health Technology Assessment Workshop Panel 1994; Institute of Medicine 1995, 1996, 2000, 2004, 2005; Presidential Advisory Committee on Gulf War Veterans' Illnesses: Special Report 1996, 1997). In the UK, over 6% of the 53 472 1991 Gulf War veterans have sought evaluation through the Ministry of Defence's Gulf Veterans Medical Assessment Programme (GVMAP). Of these, 75% were diagnosed as 'well'. Of the 'unwell', the most common diagnosis was mental disorder (21%) and only 3% were thought to have a war-related condition (Bale & Lee 2005). Despite mostly negative clinical and research findings, fully 17% of UK Gulf War veterans describe themselves as suffering from Gulf War Syndrome (Chalder *et al.* 2001). Moreover, nearly 30% of US Gulf War veterans have sought service-connected disability benefits and nearly 87% of processed claims have resulted in benefits, including some 3200 veterans who have received compensation for disability associated with unexplained symptoms (Veterans Benefits Administration 2002). Five per cent (215) of Canadian Gulf War veterans have received disability pensions for idiopathic symptom syndromes such as chronic fatigue syndrome, fibromyalgia and irritable bowel syndrome.

In addition to clinical and epidemiological research, the Gulf War Syndrome controversy has prompted medical historians to rediscover an extensive international literature on poorly understood war-related symptom syndromes (for a detailed discussion, see Jones 2006). Controversial syndromes have occurred during and after virtually every major war dating back at least as far as the Crimean War of the 1850s and the US Civil War (Hyams *et al.* 1996; Jones *et al.* 2002). These postulated illnesses have gone by a variety of different names, including Da Costa's syndrome, soldier's heart, shell shock, effort syndrome, neurocirculatory asthenia and battle fatigue.

Historically, the causes of these war syndromes have been elusive, typically resulting in polarized debates focused on competing psychological vulnerability versus biomedical disease explanations. These scientific and political debates have mirrored the current controversy regarding Gulf War Syndrome, wherein various stakeholder groups tend to take up one-sided positions and wage public battles over the legitimacy of putative exposures and postulated war syndromes (see Durodié 2006).

Unresolved disputes over aetiology and associated scientific, political, legal and media discussions may have unintended and negative public health consequences, including social divisions, unwarranted community health worries and elevated mistrust between military veterans and healthcare providers who are charged with meeting their health needs (Engel *et al.* 2002). Public controversy and resulting individual distress may also alter potentially beneficial health behaviours, such as care-seeking, compliance with medical advice and alcohol and tobacco use. These behaviours may then exacerbate underlying medical and psychosocial sources of symptoms and disability.

Taken together, each war sets into motion an expanding legacy of chronic physical, emotional and

Table 1. Common predisposing, precipitating and perpetuating factors that lead to chronic, idiopathic symptoms and associated disability.

predisposing factors	precipitating factors	perpetuating factors
heredity	biological stressors	harmful illness beliefs
early life adversity	acute physical illness	labelling effects
chronic illness	psychosocial stressors	misinformation
chronic distress or mental illness	acute psychiatric disorders	workplace and compensation factors
	epidemic health concerns	social support factors
		physical inactivity
		chronic illness
		poorly integrated care

fiscal consequences that ultimately affect not only veterans and their families but the larger society as well. However, prevailing disease management approaches to prevention and healthcare delivery have not adequately addressed the symptoms and disability that occur among war veterans. In particular, there is a critical need for innovative and comprehensive healthcare models that can better address chronic war-related idiopathic symptoms. The need is especially urgent given current deployments of US, UK and other military forces to Iraq and Afghanistan for extended tours of combat duty.

What can be done to manage future Gulf War Syndromes? Scientifically, the answer to this question is still in development. In this paper, we will elaborate a model of post-war healthcare that targets idiopathic symptoms. We will then describe international efforts to elucidate, develop and adopt this model over the 15 years since the 1991 Gulf War. Finally, we will discuss ongoing public health and health services research initiatives and suggest future improvements.

2. CHRONIC IDIOPATHIC SYMPTOMS AMONG WAR VETERANS

The principal clinical challenge subsequent to the 1991 Gulf War is clearly idiopathic symptoms and related syndromes (Ismail & Lewis 2006). What have we learned from research after the 1991 Gulf War and from studies of chronic idiopathic symptoms and disability in other contexts that can help us develop effective ways of preventing or mitigating future war syndromes? First, it should be noted that idiopathic symptoms are a significant problem in all adult populations. Conservative estimates indicate that 25–30% of symptoms in a community are idiopathic (Kroenke & Price 1993). Moreover, primary care physicians identify a medical explanation for symptoms in less than one of seven patients in whom a medical explanation is not apparent during the initial clinic visit (Kroenke & Mangelsdorff 1989). Chronic idiopathic symptoms increase healthcare use, but invasive diagnostic approaches applied to these symptoms often lead to more harm, patient dissatisfaction and provider frustration than medical benefit (Twemlow *et al.* 1997; Kouyanou *et al.* 1998).

Chronic symptoms, idiopathic or not, contribute substantially to patient levels of disability (Escobar *et al.* 1987; Kroenke *et al.* 1994). Chronic symptoms and associated disability often lead to and are produced by distress, worry, anxiety and depression (Von Korff &

Simon 1996; Armenian *et al.* 1998; Gureje *et al.* 1998, 2001). These symptoms vary widely in severity from single symptoms that are mild and transient to multiple symptoms that are chronic and disabling (Katon *et al.* 1991). Clinical outcomes related to chronic idiopathic symptoms are strongly correlated with biopsychosocial influences that may be characterized as predisposing, precipitating and perpetuating factors (table 1; Walker *et al.* 1998; Engel & Katon 1999). Cognitive factors, like community or individual beliefs regarding the nature and health impact of environmental and psychological exposures, behavioural factors (like patterns of healthcare use) and health service experience (including iatrogenic harm and conflicting provider and patient explanations for symptoms) may hasten the onset and perpetuate the course of chronic, idiopathic symptoms and related disability (Engel & Katon 1999).

Unfortunately, some clinical approaches do not consistently mitigate chronic idiopathic symptoms, but may actually worsen and perpetuate them. Although research has identified evidence-based treatments for chronic idiopathic symptoms and associated disability (O'Malley *et al.* 1999; Kroenke & Swindle 2000), differing provider and patient explanations for these symptoms contributes to the frustration and dissatisfaction with care consistently observed in empirical studies (Lin *et al.* 1991; Hahn *et al.* 1994; Walker *et al.* 1997). If a healthcare visit for chronic idiopathic symptoms occurs in the context of a public dispute over the causes of and blame for symptoms and disability after some putative exposure, the provider–patient relationship may be strained further or even become outwardly adversarial (Quill 1985; Engel *et al.* 2002). Other times, the provider may unwittingly over-respond to these symptoms by ordering too many diagnostic procedures, an approach that can lead to iatrogenic harm (Kouyanou *et al.* 1998).

A difficult healthcare encounter may foster provider–patient differences, disagreements and mistrust over symptoms that tend to mirror concurrent public debates over the causes of illness in a community (Engel *et al.* 2002). In contrast, collaborative negotiation of differing physician–patient perceptions of illness and development of a mutually acceptable model of illness may lead to increased patient satisfaction and decreased health concerns (Von Korff *et al.* 1997).

Fortunately, there is an effective population-based healthcare model that is being developed, which is

grounded on our current understanding of chronic idiopathic symptoms.

3. THE CONCEPTUAL BASIS OF POPULATION-BASED CARE

The goal of population-based healthcare is to achieve maximum efficiency and effectiveness through an optimized mix of 'population-level' and 'individual-level' interventions. However, these two separate levels of healthcare have to be linked together through primary healthcare using a public health approach involving both passive and active health surveillance.

As the name implies, population-level care employs interventions that affect whole populations. Examples include public service announcements (e.g. antismoking campaigns) or changes in laws or policies (e.g. speed limit reduction; Rose 1992). In comparison, individual-level care uses interventions that target specific patient groups defined by a common illness or healthcare need. These two approaches generally offer opposing strengths and weaknesses, which tend to balance out each other when coordinated in population-level healthcare.

Exposure of an entire community to an intervention can lead to a large community benefit, even though the average benefit per individual is small. However, a population-level intervention must be exceedingly safe and relatively inexpensive because everyone in the population is potentially exposed to it, including many who are healthy. In contrast, individual-level intervention allows the use of higher risk and more costly interventions because the return benefits are substantial when used only among individuals in more need of care.

A major drawback of individual-level intervention is that illnesses usually occur along a continuum of severity and risk. Many individuals with relatively minor symptoms or needs go undiagnosed and untreated. Therefore, individual-level interventions address only a small proportion of the full magnitude of a health problem. Consequently, efforts to achieve an optimal mix of population- and individual-level interventions are the major features of population-based healthcare.

Population-based care relies on organized clinical (i.e. individual-level) services linked through primary care to a programme of pre-clinical and population-level prevention. For this approach to work efficiently, community subgroups with elevated risk or with existing symptoms and disability must be identified and a mechanism to track health outcomes and help match key subgroups to specific interventions has to be devised (Wagner *et al.* 1996).

Within the population, only a small proportion of incident symptoms become chronic, but individuals with chronic symptoms present more frequently to healthcare settings than individuals with transient symptoms (Engel & Katon 1999). This spectrum of chronicity, severity and healthcare use results in a healthcare system gradient: individuals from general population samples report the fewest symptoms and least severe illness on average, whereas patients from samples of specialty care clinics report the most

Figure 1. Schematic of population-based healthcare for chronic post-war idiopathic symptoms and associated disability.

health problems and individuals from primary care samples report intermediate levels of ill health (Green *et al.* 2001).

This distribution of idiopathic symptoms across various levels of healthcare has implications for when, where and how to intervene—whether pre-clinical, primary care or tertiary care—to reduce the overall community burden of idiopathic symptoms. For large military populations, incidence reduction (preventing the onset of war-related symptoms) generally has to rely on population-level interventions applied before chronic symptoms and disability occur or become chronic (i.e. before healthcare is sought).

Following wars, efforts to reduce duration and prevent future episodes of idiopathic symptoms and disability are best achieved in the primary care setting because this tends to be where care is first sought. Additional attempts to reduce morbidity associated with chronic symptoms and disability (e.g. psychosocial distress, psychiatric disorders and decrements in occupational functioning) may be best initiated in primary care settings with on-site assistance from selected specialists, i.e. the 'collaborative primary care' approach. More intensive specialty care programmes for post-war symptoms and disability are then employed for veterans who are refractory to interventions at these initial levels of care and emphasize rehabilitative efforts to increase functioning and reduce iatrogenic harm that may result from overaggressive or invasive diagnostic and therapeutic strategies. Figure 1 and table 2 provide a summary description of each level of care in this model.

4. LEVELS OF CARE FOR WAR SYNDROMES

(a) *Pre-clinical prevention*

Chaos, loss of control, multiple health fears and chronic idiopathic symptoms are common soon after catastrophic events like combat and terrorist attacks. Because acute fears, concerns and symptoms can become chronic, preventive intervention is often recommended in the immediate aftermath of a traumatic event. However, a critical reassessment of differing psychosocial interventions offered immediately post-trauma is occurring. Recent research findings suggest that at least one commonly recommended acute intervention, critical incident stress debriefing, is not effective and may even be harmful.

Table 2. Overview of a stepped approach to population-based healthcare for idiopathic post-war symptoms.

step	emphasis	setting	goal	general approach	information systems
1	post-war symptom prevention	pre-clinical	incidence and prevalence reduction	general prevention efforts based on exposures and proximity	identify precipitating events
2	routine primary care symptom mitigation	primary care	identification and prevalence reduction	primary care provider delivers diagnostic services, low intensity treatments and psychosocial support	identify symptoms and concerns
3	collaborative primary care symptom reduction and disability prevention	primary care	prevalence reduction	interdisciplinary practice team intensifies care in coordination with primary care provider	identify persistent symptoms or concerns
4	intensive rehabilitative reduction of symptom duration and disability severity	specialty care	morbidity reduction	specialized multidisciplinary and multifaceted rehabilitative programmes	identify persistent symptoms or concerns combined with disability

There are four pre-clinical modalities that have been used in both the civilian and military community to prevent chronic idiopathic symptoms following trauma:

- (i) workplace screening for psychological vulnerability;
- (ii) workplace education and support networks;
- (iii) informal ('lay') debriefings after traumatic events and
- (iv) family education and support networks.

In the general workplace, educational approaches teach workers about health risks and psychosocial responses related to traumatic events. Community and workplace leaders often facilitate an early return to usual work routines and other roles in an effort to maximize post-trauma productivity. 'Town hall'-style meetings in which leaders address community concerns provide forums for information dissemination and feedback to leaders from members of the community. Telephone 'hot lines' also afford personalized contact to people with health-related questions or concerns or who desire clinical care.

For war veterans and victims of terrorist attacks, efforts to mitigate chronic idiopathic symptoms and related disability usually focus on groups at risk based on level of psychosocial, medical and geographical proximity to traumatic events or hazardous exposures. For example, the military medical system response to the September 11 Pentagon attack used several measures of proximity to estimate risk (Orman *et al.* 2002). The highest level of geographical proximity was conceptualized as first, the attacked 'wedge' of the Pentagon, followed then by the rest of the Pentagon and finally the greater Washington, DC area. Exposures of concern in decreasing order of risk included the physically injured, those attending to the injured or killed, individuals otherwise physically exposed (e.g. felt the blast, inhaled smoke) and last those who observed people being injured. Levels of emotional proximity included family, friends, colleagues and subordinates of those injured or killed, of

those in the damaged wedge and of those working elsewhere in the Pentagon.

Wide-scale pre-clinical psychological debriefings immediately following a traumatic event have been widely advocated in both the civilian workplace and military environment. However, randomized controlled trials of psychological debriefings have shown no efficacy and even the potential for harm (Wessely *et al.* 1998). Perhaps this outcome is not surprising given that most individuals do well after a traumatic experience but are vulnerable to medicalization of traumatic distress by well-meaning healthcare providers and by exaggerated expectations of a poor outcome due to misleading media reports. Workplace liability concerns and overwhelming community desires to help victims often fuel pre-clinical debriefings even in the absence of scientific support for their efficacy, but scarce community resources may be better directed toward targeted clinical efforts to recognize and intervene early among the most traumatized individuals.

Mass screening is another commonly recommended post-trauma strategy. Screening involves identification of individuals in need of clinical management, i.e. individual-level intervention delivered in a healthcare setting. Surveillance, by comparison, is the use of active and passive health measurement strategies to characterize the health of a community and its subgroups. It is often assumed that screening is harmless, but population-based pre-clinical screening has the potential to unnecessarily medicalize psychosocial concerns and there are often significant problems with false negative and false positive findings. Particularly in military and other occupational settings, forced screening has the paradoxical potential to stigmatize the exact problems one is seeking to identify. Instead, screening for post-war symptoms and disability in the privacy of the primary care setting, clinical tracking of associated outcomes and intensification of treatment for those with identified needs may be a better approach pending further research evidence regarding the overall efficacy of mass preclinical screening (Engel & Katon 1999). While the UK has adopted this clinic-based approach to screening, the United States and Canada have

Table 3. Modalities for routine primary care mitigation of chronic post-war idiopathic symptoms.

patient screening for symptoms and distress
patient education regarding chronic pain and fatigue, depression and distress
management of depression
clinician reminders
clinician feedback regarding patient outcomes
systematic consultation based on complications, non-response and persistence

initiated mass pre-clinical screening for troops returning from deployments. Canada is in the process of implementing health assessments every 2 years for all Canadian Forces. Eventually the Canadian plan is for periodic health assessment to replace immediate pre- and post-deployment assessment, avoiding the potential for biased responses based on temporal proximity of the assessment to deployment.

Pre-clinical intervention is probably the level of care in greatest need of further study and development in a population-based healthcare model. This is due to the fact that prior research is yet to yield any consensus regarding which, if any, approaches are effective or how to safely and accurately screen for psychological vulnerability in a military context.

(b) Initial primary care mitigation of post-trauma symptoms

A high prevalence of chronic idiopathic symptoms should be expected following wartime military service or terrorist attacks. Data from the general population suggest that virtually all individuals with chronic idiopathic symptoms will see a primary care provider over the course of an average year (Green *et al.* 2001). Data from the US military suggest that 90–95% of service members seek healthcare in the average year (Engel 2005). Therefore, a key population-based healthcare response following war is to provide early primary care recognition and treatment of idiopathic post-war symptoms (table 3). Once identified as expected outcomes, providers can confidently offer modest, individual-level interventions to mitigate the impact of the precipitating event and reduce the potential for perpetuating factors to prolong the symptoms. The focus on gradually intensifying treatment for those seeking care helps avoid stigma that may be introduced by screening the entire population.

Because symptoms linked to disability in the primary care setting are often idiopathic (Kroenke *et al.* 1994), a patient-centred rather than disease management approach is most effective. An appropriate approach involves limited diagnostics directed by clinical suspicion with watchful waiting to discard transient symptoms and concerns. In parallel, provider and patient collaboratively negotiate the nature, cause and treatment focus. Assessment of depressive and anxiety disorders including PTSD and introduction of evidence-based therapy for these disorders should occur early. Collaborative negotiated approaches are essential: healthcare providers often fail to communicate the degree of diagnostic uncertainty inherent in clinical practice, particularly as it relates to idiopathic

symptoms. For their part, patients frequently equate absence of a disease-based explanation for idiopathic symptoms to a psychological explanation. If the explanation is not negotiated, then patients are often offended, misinterpreting ‘idiopathy’ for ‘imaginary’.

Among war veterans, many of whom have experienced diverse health risks, the possibility of future mental health consultation should be destigmatized by describing it early to affected patients as ‘routine care for patients distressed by disabling post-war symptoms’. In this way, individuals later referred to psychiatry may be less likely to feel their primary care provider is rejecting them or contesting the validity of their symptoms.

Primary care provider’s attempts to understand a patient’s views and expectations regarding chronic post-war idiopathic symptoms may result in short-term improvements in patient satisfaction (Jackson *et al.* 1999) and may enhance patient–provider trust more than blanket provider reassurances. Some providers prefer to directly confront improbable illness worries, but these confrontations often offend patients and can disrupt continuity of care. Efforts to offer explanations, answer questions, display empathy and define problems the patient considers relevant are advised and may be aided with timely educational literature on common post-war health concerns. Patients presenting with health concerns heightened by the news media or Internet appreciate the opportunity to review these concerns with clinicians aware of the war-related health issues of the day.

The clinical decision to invoke the next level of care for post-war symptoms and disability—collaborative primary care—hinges on: persistence of symptoms and associated disability, whether or not the patient adheres to self-care and follow-up, and whether complicating medical problems exist.

(c) Collaborative primary care

There comes a point at which post-war symptoms and disability either improve with primary care management or persist and require intensified individual-level care. Once idiopathic symptoms and disability persist beyond about three to six months, routine primary care management typically requires supplementation by a specialist operating from within the primary care setting, which is described here as collaborative primary care.

A summary of collaborative primary care approaches may be found in table 4. An interdisciplinary practice team located in a primary care setting is critical (Wagner 2000). Involvement of the practice team in a parallel process of multifaceted care delivered within primary care provides needed options for physicians when provider–patient tensions may be developing or when the issues of concern are beyond the abilities or scope of the primary care provider. In the war-related healthcare context, this parallel coordinated process of care also affords patients with more extensive opportunities to communicate concerns about possible ‘toxic’ exposures encountered during the war, to engage all available social supports and to obtain assistance aimed at reducing distress and disability. Using the primary

Table 4. Modalities for collaborative primary care reduction of chronic post-war idiopathic symptoms.

interdisciplinary practice team with primary care provider integration
clinical risk communication, with timely health risk information for clinicians and patients
patient education regarding symptoms and disability
physical and psychosocial reactivation efforts
negotiated goal setting
collaborative problem-solving

care clinic to deliver psychosocial and behavioural treatments also minimizes potential stigma sometimes associated with these measures and simplifies care for patients. This approach may improve rates of follow-up and foster continued involvement of primary care providers in place of early referral and specialty care management.

Research on successful consultative care for idiopathic symptoms in general suggests useful practice team responsibilities (Smith *et al.* 1995; Von Korff & Moore 2001). In general, the practice team should ensure that patients with chronic war-related idiopathic symptoms and associated disability have a single primary care physician who coordinates care, sees patients regularly, and sparingly applies invasive diagnostic testing and potentially toxic pharmacotherapies. The practice team helps the primary care physician to foster active patient coping, including intensive education and modest physical activity as appropriate, to coordinate interdisciplinary treatment planning and to monitor for the need for more intensive levels of care. Practice team interventions are best administered in a stepped fashion so that simple approaches are offered first before more intensive efforts are considered.

Common elements of collaborative primary care include: screening for treatable medical and psychological health problems; on-site mental health consultation; cognitive-behavioural and problem-solving therapies aimed at medication adherence, depression, idiopathic symptoms and disability; physical exercise and relapse prevention; self-care videotapes, pamphlets and other education materials; structured follow-up that relies on multiple methods (visits, telephone, email or web-Internet) and longitudinal case-management (Powell *et al.* 2001).

Practice teams can also enhance clinical efforts at so-called 'risk communication'—that is, communications regarding potential health risks such as environmental hazards that are contentious and are raised for discussion in a 'low-trust, high-concern' context such as in the immediate aftermath of war or a terrorist attack. In the primary care setting, if a patient harbours conspiracy fantasies or other beliefs that foster passivity or may increase provider-patient conflict, the practice team can listen, help patients test their beliefs and prescribe active coping strategies that promote functioning.

(d) *Intensive rehabilitative care*

When collaborative primary care is not sufficient, there are a number of intensive rehabilitative care approaches

used to reduce the disability associated with chronic idiopathic war-related symptoms. These intensive rehabilitative programmes may be delivered in either an inpatient or ambulatory care setting as resources allow. The characteristics and components of these programmes typically include:

- (i) 3–4 weeks of inpatient or 10–15 weeks of once or twice weekly ambulatory care;
- (ii) structured and behavioural intensive rehabilitation efforts;
- (iii) multi-modal strategies;
- (iv) physical and psychological reactivation;
- (v) graduated return to work; and
- (vi) planned practice team follow-up.

Model programmes for chronic war-related idiopathic symptoms and disability are usually multifaceted and multidisciplinary, occur in specialized, non-primary care settings and have involved either a 3–4 weeks inpatient or intensive outpatient programme or a 10–15 weeks programme of weekly or biweekly individual or group visits (Flor *et al.* 1992; Kroenke & Swindle 2000). Medical and psychosocial approaches are combined with a structured and supervised physical activation plan. These programmes treat disability as a behaviour amenable to modification, regardless of medical aetiology.

The Canadian version of this intensive rehabilitative care employs a multidisciplinary clinical team with a 2 year period of monthly care coordinated by an internist. Patients with a primary or coexisting psychiatric disorder are seen at Operational Trauma and Stress Support Centres staffed by psychiatrists, psychologists, social workers, chaplains and community health nurses.

Commonly employed cognitive-behavioural approaches to chronic idiopathic symptoms and disability help patients assess their beliefs regarding cause, prognosis and treatment and identify attitudes that are delaying progress, and substitute those that lead to improved function. Empirical trials have shown the benefits of cognitive-behavioural therapy for a range of idiopathic symptom syndromes and associated disability (Speckens *et al.* 1995; Kroenke & Swindle 2000; Price & Couper 2000; Deale *et al.* 2001; Prins *et al.* 2001).

Physical exercise is another clinical strategy that has been shown to have a number of positive effects on health and well-being across many health conditions, and efforts to bolster physical activation and functioning are common in multifaceted programmes for chronic symptoms and disability (McCain *et al.* 1988; Fulcher & White 1997; Frost *et al.* 1998; Wearden *et al.* 1998). Evidence favours supervised, graduated and early return to work for improving role functioning among patients with chronic symptoms and disability. For example, studies of patients with low back pain suggest that a return to modified work can be successful (Frank *et al.* 1996), while work restrictions diminish the likelihood of return to work and do not reduce absenteeism or back pain recurrences (Burton & Erg 1997).

5. ESSENTIAL HEALTH INFORMATION SYSTEMS

A carefully designed health information system is essential for effective population-based healthcare (Wagner *et al.* 1996). Information systems are computer-automated tools designed to capture data that can be used to inform clinicians regarding patient status, to assist clinicians and administrators interested in monitoring and improving the quality of care and to guide policy makers attempting to assess population needs and determine appropriate staffing levels. Information systems depend on three primary components for facilitating care of chronic idiopathic symptoms and associated disability:

- (i) *Health information systems*—‘passive’ computer automated health surveillance systems that capture data that is mainly input by providers during routine healthcare processes, like prescriptions, diagnoses and clinical referrals.
- (ii) *Health monitoring systems*—‘active’ health surveillance systems capture patient-reported data using brief surveys and similar methods.
- (iii) *Expert computer systems*—automated data processing that results in reports that identify high-risk patients and groups and provide feedback for clinicians and policy makers regarding indicators of healthcare quality.

The health information system records prioritized medical problem lists and measures of healthcare use (e.g. outpatient, inpatient and pharmacy services and various procedures), healthcare costs, presenting symptoms, primary care providers, usual place of care, patient contact information and disease specific data for developing clinical registries (Katon *et al.* 1997). These data, combined with data from active health monitoring approaches (e.g. patient-reported symptoms and disability), can be used to identify high-, intermediate- and low-risk groups for intervention and tracking.

Expert computer systems are used to process raw surveillance data into usable tools for community leaders and healthcare providers. Expert system tools aid clinical management, patient follow-up, treatment and policy decisions. Examples of expert computer system tools include registries, reports, reminders, clinical indicators, feedback systems, guideline recommendations and appropriate patient education materials or outcomes monitoring scales.

Effective pre-clinical, primary care, collaborative primary care and intensive rehabilitation strategies for post-war idiopathic symptoms require longitudinal assessments and tracking in order to maintain the linkage between ascending levels of healthcare and to facilitate population-based approaches to prevention and care. A multifaceted information system comprised of health information systems, health monitoring systems and expert computer systems is necessary for achieving these aims and for bringing disparate levels of healthcare into communication with one another.

6. MANAGING FUTURE WAR SYNDROMES

What evidence exists that the population-based healthcare approach is feasible or effective? Efforts are in an early stage, but a series of research, policy and practice initiatives focused within the US Department of Defense (DoD) and Department of Veterans Affairs (VA), the United Kingdom, Canada and other nations suggest the model is feasible and that many elements are effective. In addition, these initiatives indicate that the model offers a roadmap for improving community health system response to acts of mass terrorism (Engel *et al.* 2003).

Development of a population-based healthcare approach has been greatly facilitated by increasing recognition that post-war and post-disaster health problems are a significant health issue that has to be addressed. Increased levels of support and cooperation have therefore developed within various Western governments on these health issues. One of the most important examples of government understanding and support was the US enactment in 1998 of legislation that provides 2 years of free healthcare from the VA for war veterans after they leave active military duty.

In addition to VA healthcare, DoD can also offer extended healthcare coverage beyond the period of active service due to legislation enacted in 2004, including six months of healthcare coverage for Reservists and National Guardsmen who have left active duty and are returning to civilian life under the ‘Transitional Assistance Management Program’ and TRICARE. The extensive VA and DoD healthcare coverage among Reservists and National Guard personnel is particularly important because these part-time troops are increasingly being called up to serve for extended periods of time in Iraq and Afghanistan.

While in the United States the VA is the largest single healthcare provider in the world, both the Australian and the Canadian VA systems are not directly involved with the provision of healthcare. Australia, Canada and UK have elaborate systems of national healthcare, which means that when, for example, a Canadian veteran enters the civilian work force, they receive all care free but from civilian healthcare providers. Veterans Affairs Canada assists veterans in navigating the disability pension process and refers appropriate veterans to Department of National Defence health resources to aid with diagnosis and treatment.

Although healthcare is free in Canada, UK and Australia, civilian healthcare providers may not understand veterans’ health concerns when related to unique wartime experiences. This is also a problem in USA for veterans when they obtain healthcare in the private sector.

Canadian, US and Australian VA and Defence Departments as well as UK Ministry of Defence are collaborating nationally and internationally at unprecedented levels in an effort to learn from each other and share information that can aid those veterans who obtain assistance from the civilian healthcare system. Working with veteran service organizations is important in this regard, because veterans trust these

organizations and look to them for advocacy-based information regarding medical and other benefits.

(a) Post-war health services research agenda

A strong governmental commitment for the provision of healthcare to war veterans substantially facilitates efforts to manage chronic idiopathic symptoms among those who have participated in military conflict. Three advances in population-based healthcare may be highlighted: (i) development of a post-war health services research agenda; (ii) implementation of primary care practice guidelines on post-deployment healthcare delivery and (iii) exploration of novel healthcare guideline implementation strategies. The following discussion offers descriptions of these three advances on an international scale.

In the early 1990s, concerns over a possible Gulf War Syndrome led to an international understanding that an ongoing post-war health services research agenda with a specific cadre of scientific and clinical expertise was necessary. To respond to these concerns, in 1993, the VA implemented the Persian Gulf Veterans' Registry and the Ministry of Defence in the UK started the GVMAP to provide systematic clinical evaluations for concerned Gulf War veterans (Coker *et al.* 1999; Department of Veterans Affairs 2002). DoD initiated the Comprehensive Clinical Evaluation Program (CCEP) in 1994 (Joseph *et al.* 1998). These programmes also functioned as extensive clinical registries to facilitate research into emerging questions regarding toxic wartime exposures and potentially related chronic, idiopathic symptoms.

In Canada, a Gulf War clinic with a national referral base was opened in Ottawa in 1995. A multi-disciplinary team working in a collaborative environment undertook the most extensive evaluations ever undertaken in a veteran population. Patient satisfaction was generally high and the treating team gained significant expertise and experience in the management of war-related health concerns and idiopathic symptoms among 1991 Gulf War veterans. However, one clinic for all of Canada did not allow primary care assessments by clinicians at local bases, made it difficult to conduct follow-up examinations and presented barriers for family and workplace involvement in strategies to return veterans to health and productivity. An evaluation of the single National Gulf War Clinic after almost 3 years of operation led to a number of changes, including the closure of the clinic in late 1997.

The closure of Canada's Gulf War clinic necessitated establishment of decentralized expertise at a number of centres across the country. Operational trauma and stress support centres were started at larger bases across Canada in 1999. These multi-disciplinary centres developed expertise and local level experience in the holistic management of returning veterans and their families. These centres have established liaisons with local primary care clinics to facilitate referral and education of routine primary care providers.

Military and veteran programmes for 1991 Gulf War veterans, imperfect as they were, led to many lessons regarding post-war healthcare delivery

(Institute of Medicine 1997, 1998), research priorities (Gray *et al.* 1998; Kroenke *et al.* 1998; Roy *et al.* 1998; Engel & Katon 1999) and individual needs of veterans (Institute of Medicine 1997) in the USA, UK and Canada. In response, the US Defense Department in 1999 established the Deployment Health Clinical Center with the mission of improving post-deployment healthcare using specialized clinical programmes, health services research and educational approaches.

In 2001, the VA established two war-related illness and injury study centres or 'WRIISCs', at the Washington, DC and East Orange, NJ VAMCs. These research, education and clinical care centres provide specialized healthcare for combat veterans from any hazardous deployment who experience difficult to diagnose but disabling illnesses. VA further developed its clinical registry concept using advances in its electronic patient record system, which now captures diagnostic and other information for every inpatient and outpatient encounter. Using this approach, the VA is conducting longitudinal surveillance of every Iraq and Afghanistan war veteran who enrolls for VA care in the USA (Kang & Hyams 2005).

An intensive rehabilitative programme based at Walter Reed Army Medical Center in Washington, DC, for Gulf War veterans with treatment-refractory symptoms was developed by DoD as part of the CCEP (Engel *et al.* 1998). The programme, still in existence, employs chronic disease management, graded physical activation and cognitive-behavioural approaches as key therapeutic elements. The programme has treated veterans with similar symptoms and military service-related health concerns as those among Gulf War veterans after the conflicts in Bosnia and Kosovo in the mid-1990s, the 11 September 2001 Pentagon attack and recent military operations in Afghanistan and Iraq.

Two of these essential rehabilitative elements, graded physical activation and cognitive-behavioural therapy, were evaluated in a randomized controlled trial carried out in 18 VA and two DoD sites in the USA. Exercise and cognitive-behavioural therapy were chosen for study because of their demonstrated efficacy in controlled trials of patients with similar idiopathic syndromes such as fibromyalgia and chronic fatigue syndrome (Fulcher & White 1997; Wearden *et al.* 1998; Kroenke & Swindle 2000; Price & Couper 2000; Richards & Scott 2002). The trial evaluated 1 year treatment outcomes for nearly 1100 Gulf War veterans with chronic idiopathic symptoms and associated disability (Donta *et al.* 2003). The CDC developed the case-definition employed in the study, called 'chronic multisymptom illness', using statistical and clinical methods (Fukuda *et al.* 1998). In a two-by-two factorial research design, veterans were randomized to one of four treatment arms that delivered 12 weeks of either physical activation, group cognitive-behavioural therapy or both, versus usual post-war symptomatic care.

The results of the study were similar to those found in pilot studies (Engel *et al.* 2000), revealing modest improvements in symptoms of fatigue and cognitive impairment and in mental health functioning with

both graded physical activity and with cognitive-behavioural therapy (Donta *et al.* 2003). While the cognitive-behavioural approach is not curative, it offered partial symptom relief and improved quality of life for many veterans with chronic post-war idiopathic symptoms.

In Canada, the 1991 Gulf War marked the beginning of a period of closer collaboration between its Department of National Defence and Veterans Affairs Canada. The realization that idiopathic physical symptoms and increases in general health concerns were common after all deployments and that the civilian medical community needed assistance in caring for war veterans led to memoranda of understanding between Department of National Defence and VA Canada in the late 1990s. These memoranda allowed VA Canada to refer veterans to Department of National Defence physicians with specific expertise in post-deployment health and to Defence Operational Stress Centres. In 2003, Department of National Defence and VA Canada launched a Joint Release Transition Project out of recognition that the transition to civilian life was especially difficult for those members being medically released. This programme used case managers working at clinics across the country to assist veterans in navigating resources and entitlements in Department of National Defence and VA Canada, as well as the civilian healthcare system. The approach comprises part of an extended collaborative practice model that crosses various Canadian federal departments.

The combined strategy of post-war clinical registries, health surveillance, longitudinal case management, intensive post-war rehabilitative programmes and centres of war-related healthcare delivery and research expertise have all emerged from these governments' attempts to address the health concerns of veterans who served in the 1991 Gulf War. These are important international advances in the continuum of war-related healthcare.

(b) Primary care practice guidelines on post-deployment healthcare

In evaluating the adequacy of DoD and VA diagnostic programmes for 1991 Gulf War veterans, healthcare scientists representing the US Institute of Medicine concluded that a systematic quality improvement programme was needed for post-war healthcare programmes. The panel recommended clinical practice guidelines (CPG) as one important early step in achieving that objective (Institute of Medicine 1998). Consequently, beginning in 1999, a collaboration of nearly 50 clinicians, scientists and health policy experts from the federal sector and academic medicine in the USA developed a clinical practice guideline for assessing, evaluating and treating returning military service members with deployment-related health concerns. This guideline, the 'DoD & Veterans Health Administration Clinical Practice Guideline for Post-Deployment Evaluation and Management' (PDH-CPG; see http://www.pdhealth.mil/clinicians/PDHEM/Toolkit/view/2/guideline_ver1.2.doc), underwent piloting in 2001 at selected medical facilities from high deployment sites in the Army,

Air Force, Navy and Marine Corps. Final implementation of the guideline was completed in early 2002 (Farley *et al.* 2002).

Complementary CPG were developed for use among patients identified in post-war assessments with chronic idiopathic pain and fatigue or with major depressive disorder (see <http://www.oqp.med.va.gov/cpg/cpg.htm>). All of these practice guidelines employed a process of evidence-based guideline development pioneered within the VA and implementation strategies organized with the assistance of RAND Corporation investigators (Nicholas *et al.* 2001).

The main goal of PDH-CPG is to facilitate, support and improve the care provided for recently deployed veterans with post-deployment health concerns. As envisioned, the guideline has already spawned new health services research and clinical quality improvement efforts. Features of PDH-CPG include an emphasis on primary care, primary care screening for deployment-related health concerns and centralized web-based risk communication and clinician implementation support (see PDHealth.mil at <http://www.pdhealth.mil>). PDH-CPG offers clinical evaluation and follow-up guidance, a clinical framework for communicating effectively about military-related health risks and other supporting clinical and patient education tools. Several metrics are used to help track guideline implementation.

Within the US Defense Department, screening for health concerns is facilitated using a 'military-unique vital sign' for deployment-related health concerns. Evidence suggests that this vital sign effectively identifies patients with idiopathic physical symptoms, depression, general psychosocial distress and low satisfaction with care (Jaffer *et al.* 2003). PDH-CPG prescribes that all DoD beneficiaries visiting primary care clinics are routinely asked, 'Is your visit today for a deployment-related health concern?' The answer is recorded as yes, no or may be. Affirmative responses prompt care in accordance with the guideline. To facilitate development of population-based, clinical registries, visits that the patient reports are due to a deployment-related health concern are coded by DoD using a unique ICD-9-CM v-code (v. 70.5_6).

Patients with health concerns are prescribed extra or extended visits to accommodate discussions of concerns, symptoms and health conditions. Within the PDH-CPG, guidance is offered to clinicians regarding the facilitation of communication around war-related health concerns for four main types of patient presentations: (i) patients without deployment-related health concerns; (ii) those with concerns who are asymptomatic; (iii) those with concerns and a diagnosable disease and (iv) those with concerns and idiopathic symptoms, i.e. the possible war syndrome patient.

Programmatic efforts by US Defense Department to provide health services for individuals affected by the September 11 Pentagon attack help illustrate how recent post-war healthcare initiatives may also lead to advances in healthcare system response following an event with homeland security implications. The Army Medical Department initiated 'Operation Solace' in

the greater Washington, DC, area following the Pentagon attack to ensure that individuals with related health concerns received appropriate medical assistance. Piloting of PDH-CPG was nearly complete and efforts to implement it were undertaken in area primary care clinics.

Primary care patients were asked a modified version of the military-unique vital sign to ascertain if a visit was due to deployment, bioterrorism or terrorism attack-related health concerns. Each implementing clinic used an 'Operation Solace care manager'. The care manager's task was to help clinics to integrate guideline practices into their process of care. When a patient indicated a concern on the vital sign, the care manager helped the patient and the primary care provider to elucidate September 11-related concerns, resolve barriers to care, improve continuity of care and coordinate referrals and follow-up.

During a six month period in 2002, 100 patients who screened positive on the military unique vital sign completed a survey to define the reason for the visit and other health status variables. Deployment was the most common reason for the patients' concern, followed by the terrorist attack. September 11-related health concerns constituted less than 1% of primary care visits to participating DoD clinics, but compared to data from civilian primary care settings, the patients with concerns reported significant elevations in physical symptoms, post-traumatic distress, mental disorders and healthcare use, and lower levels of satisfaction with care (Jaffer *et al.* 2003).

Operation Solace illustrates how population-based healthcare approaches can leverage primary care resources to improve overall healthcare system responsiveness following war and other traumatic events. Future health services research needs to address whether the use of a care manager can improve the longitudinal care of patients with trauma-related health concerns, improve patients' satisfaction with their healthcare, reduce high use of health services and maximize health outcomes. From a population health perspective, a public commitment by the government to improve healthcare for those injured in the line of military duty may improve institutional trust among serving military personnel and veterans.

7. CONCLUSION

Typical disease management strategies will only offer solutions for a small proportion of the symptoms and disability in a community following war or a terrorist attack. In contrast, a population based healthcare approach offers a more comprehensive solution for government-run healthcare systems for military personnel and war veterans as well as for civilian communities preparing for a possible terrorist attack. This model is feasible, graduated in implementation, interdisciplinary, multifaceted, lends itself to evaluation and improvement and is increasingly used in the US, Canada and other Western countries caring for military personnel and war veterans. It optimally combines public health perspective with patient-centred care based on individual patient needs.

These linkages between public health and individual patient care approaches are guided by an emphasis on primary care and on well-developed health information systems.

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