

Gulf War Illness: Lessons from medically unexplained symptoms

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Abstract

Service in the Persian Gulf in 1991 is associated with increased reporting of symptoms and distress in a proportion of those who served there. Yet despite clear evidence of an increase in symptom burden and a decrease in well being, exhaustive clinical and laboratory based scientific research has failed to document many reproducible biomedical abnormalities in this group. Likewise, there has been no evidence of an increase in disease related mortality. Formal psychiatric disorders are twice as common in Gulf War veterans, as might be expected in the aftermath of any conflict, but this too is insufficient to explain the ill-health observed. Many service personnel who returned unwell believe that they have Gulf War Syndrome, and that their ill-health is due to exposures that they encountered in theatre. Research on multiple exposures to date has not generated a plausible aetiological mechanism for veterans' ill-health.

Even if medical research has failed to provide a satisfactory explanation, it remains the case that many of those affected continue to be unwell and disabled some 15 years after returning from combat. For this reason, it is time that more attention is given to developing effective interventions to relieve their ill-health and distress. In this review we discuss the importance of the wider social context, individual illness beliefs and attributions and go on to outline a model of continuing ill-health in Gulf veterans. The review concludes with some suggestions for future research priorities, in particular the need for further qualitative studies to further our understanding of the illness, in order that better treatments may be developed.

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1. Introduction

In 1991, nearly 1 million servicemen and women from the United States, United Kingdom, France, Canada, Australia, Denmark and 30 other nations were deployed in the Persian Gulf. After a concentrated air assault, the ground offensive targeted against the Iraq invasion of Kuwait lasted only 100 hours and was one of the shortest and most effective periods of land-based conflict in history. With fewer than 400 casualties in Allied Forces troops (approximately half of which were due to accidents and “friendly fire” rather than combat), it was hailed as a resounding military success, and a testament to the efficiency and omnipotence of the new technologies of war, the so called “revolution in military affairs” (Cordesman & Wagner, 1996).

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Within months of service personnel returning, the first reports of ill-health in US returnees began to emerge on websites and in primary care clinics. Early studies were based on anecdotes and apparent clusters of ill health and/or birth defects. In response, self-selected voluntary registers were instituted (Murphy et al., 1999). Later these were followed by larger population-based epidemiological studies, and these were collated in turn into comprehensive and definitive meta-analyses/systematic reviews of the evidence base both in the USA (Institute of Medicine, 1999, 2001) and UK (Medical Research Council, 2003).

An increase in distress and unexplained symptoms is beyond dispute. Gulf veterans report having more symptoms than non-Gulf veterans (Fukuda et al., 1998; Gray et al., 1996; Unwin et al., 1999) and suffer more severely from them. Common complaints range from non-specific constitutional symptoms such as tiredness and headache, to specific neurological complaints such as numbness and limb weakness (Unwin et al., 1999). Cognitive complaints such as loss of concentration, memory problems and low mood are also common (David et al., 2002). Similar clinical pictures have now been reported from the UK (Cherry et al., 2001b; Unwin et al., 1999), Canada (Goss Gilroy Inc., 1998), USA (The Iowa Persian Gulf Study Group, 1997), Australia (Ikin et al., 2004; Kelsall et al., 2004) and Denmark (Ishoy et al., 1999). In the meantime, the term Gulf War Syndrome (GWS) has entered the lexicon to describe these symptoms, although it is almost certain that no actual new syndrome is involved (Institute of Medicine, 2001).

All commentators point out that there were several challenging methodological problems in carrying out Gulf War research, some of which were only partially overcome. These difficulties have arisen in the main because of the significant delay between the point at which illnesses were first identified by veterans and the setting up and reporting of big epidemiological studies examining health. Contemporaneous records of health were not kept systematically by the military at that time either in the USA or the UK, and routine post-deployment health surveillance was minimal. Thus, whilst some of the research done has been prospective and followed up veterans since the war (King et al., 2000), none of the large studies have been able to use pre-deployment data; as such, recall bias for what happened in theatre or before is a major problem, as it would be for any retrospective study. Other problems include low-response rates, ascertainment bias, problems identifying suitable control groups, and problems defining meaningful outcomes to study (Hotopf & Wessely, 2005).

Studies which attempt to unpick the relationship between symptoms and exposure are particularly hampered by recall bias; it is never possible to obtain reliable, independent and contemporaneous reports of an individual's exposure during war and retrospective self report is not reliable (McCauley, Joos, Spencer, Lasarev, & Shuell, 1999; Wessely et al., 2003).

In this review, after acquainting the reader with a summary of the salient findings to date, we focus on novel ways to understand at least a part of Gulf veterans' ill-health, and consider future treatment approaches based on this approach.

2. The symptoms of Gulf War Illness

Irrespective of what symptom is inquired about, Gulf veterans report each and every symptom at about twice the rate as non-Gulf veterans, and they report symptoms of greater severity (Cherry et al., 2001a; The Iowa Persian Gulf Study Group, 1997; Unwin et al., 1999). There is no group of symptoms which is exclusive to Gulf veterans, so common symptoms are common and rare symptoms are rare, but not as rare as in those not deployed to the Gulf (Cherry et al., 2001a; Unwin et al., 1999). Factor as well as cluster analysis has confirmed that the pattern of symptoms reported does not differ in Gulf and non-Gulf veterans (Boyd et al., 2003; Doebbeling et al., 2000; Everitt, Ismail, David, & Wessely, 2002; Forbes et al., 2004; Hallman et al., 2003; Ismail et al., 1999).

It is interesting to note that the most common complaints of Gulf War Illness share significant overlap with other medically unexplained symptom/syndromes such as Multiple Chemical Sensitivity and Chronic Fatigue Syndrome (Black et al., 2000; Kipen, Hallman, Kang, Fiedler, & Natelson, 1999; Reid et al., 2001, 2002).

3. Aetiology

3.1. *What is wrong?*

By 2003, 130,000 Gulf War Veterans had been seen in the various clinics established for the purpose in US/Canada and UK (Gray, Gackstetter, Kang, Graham, & Scott, 2004). One has to conclude that if a new disease for medical

science had indeed occurred in Gulf Veterans, it seems likely that this would have been identified in the clinical and laboratory examinations performed in these large series. However, none has been seen (Gray et al., 2004).

Mortality is not increased except for a transient increase in deaths from external causes such as motor vehicle accidents (Kang, Bullman, Macfarlane, & Gray, 2002), consistent with increases in post-war mortality from external causes observed in previous conflicts (Bullmore & Kang, 1994). Hospitalization rates for serious medical conditions are not increased, although there were increases in admission rates for injuries, and asthma (Gray, Smith, Kang, & Knoke, 2000).

As neurological symptoms and neuropsychiatric symptoms (such as poor concentration and memory problems) were such common reports in ill Gulf veterans (Kelsall et al., 2005; The Iowa Persian Gulf Study Group, 1997; Unwin et al., 1999), clinical studies have focused on these areas. As with other aspects of ill-health which remain unexplained in this group, lack of objectively measured exposures to Gulf War neuro-toxicants and the absence of objective prospective measures of baseline-functioning means that there are limitations to the research. There are no consistent objective neuropsychological deficits in Gulf veterans, except those consistent with low mood (David et al., 2002; Proctor et al., 2003; Sullivan et al., 2003; Vasterling, Brailey, Tomlin, Rice, & Sutker, 2003). The handful of studies which examined the relationship between neuro-toxicant exposure and reported subsequent cognitive difficulties have mixed results. These studies relied on self-report of exposure (Sullivan et al., 2003; White et al., 2001) with one exception (McDiarmid et al., 2000). This study demonstrated neuropsychological dysfunction on a single index score - an interesting finding which would need to be replicated. When the ill-subgroups are examined a weak but consistent pattern of poor performance on select neuropsychological tasks emerges, but whether these differences can be accounted for by pre-deployment vulnerabilities, or co-morbid emotional distress/diagnoses such as depression remains unanswered (Vasterling & Bremner, 2006). Imaging studies have so far failed to demonstrate any evidence of a specific effect of Gulf War service on either brain function or structure (Vasterling & Bremner, 2006). Recent US MRI spectroscopy work appears to show isolated basal ganglia changes/reduced neuronal viability in the basal ganglia and hippocampus and altered functional dopamine status of a group of ill-Gulf veterans (Haley, Fleckenstein et al., 2000; Haley, Marshall et al., 2000). It remains to be seen whether or not these imaging changes will be confirmed by subsequent work, controlling for not just Gulf War service, but other confounders of brain function such as PTSD and emotional distress.

There have also been reports of small but significant increased rates of Amyotrophic Lateral Sclerosis (ALS) in Gulf veterans (Haley, 2003; Horner et al., 2003). It is important to bear in mind that these studies rely on small numbers and that the absence of overall increased mortality in Gulf veterans from what is a fatal disease raises the possibility that there is ascertainment bias at work (Rose, 2003). A more recent study seems to suggest that there may be mildly elevated risk of ALS for all USA veterans from World War 2 onward, a curious finding which requires further thought but does not point to a specific risk factor unique to the Gulf War (Weisskopf et al., 2005).

No evidence of any objective deficits in peripheral nerve functioning or skeletal muscle has been found to date (Davis et al., 2004; Sharief et al., 2002).

At the outset there were many claims of an increase in birth defects and fertility problems in Gulf veterans. Large scale epidemiological studies, the only way of finding if these happened more than expected, have failed to confirm most of these. The UK studies found no link between father's deployment to the Gulf and risk of stillbirth, chromosomal abnormalities, or congenital syndromes, and no link between mother's service in the Gulf and subsequent risk of miscarriage (Doyle et al., 2004; Doyle, Roman, & Maconochie, 1997; Maconochie et al., 2003). There appeared to be a slightly elevated risk of miscarriage and less well-defined abnormalities in the offspring of fathers who were deployed to the Gulf, but these findings must be interpreted with caution because of the possibility of reporting bias. Miscarriages and minor birth abnormalities are common; and it is possible and plausible that they are simply being reported more by the groups who feel that they are at risk.

3.2. *Gulf War Illness — a toxic hazard*

There is no doubt that service in the Gulf War led to potential exposure to a large number of hazard chemicals and other substances, including but not restricted to oil-well fire smoke, depleted uranium munitions, organophosphate compounds and so on. In addition, many personnel received a variety of medical counter-measures such as pyridostigmine bromide tablets and vaccines, which, like all medical interventions, carry some risk of side effects. The question is not whether these substances can do harm — in the wrong place, at the wrong dose, to the wrong person, they can. The question is whether or not exposure occurred to sufficient numbers of people at sufficient intensity to

cause persistent ill health. There have been extensive and exhaustively conducted formal evaluations/meta analyses of the scientific literature on exposures conducted in the both the USA by the authoritative and independent National Academy of Sciences Institute of Medicine (Institute of Medicine, 2000, 2003, 2005) and in the United Kingdom by the Medical Research Council (Medical Research Council, 2003); to date, despite massive investment in multi-disciplinary research, studies on specific exposures experienced in the Gulf have failed to confirm any single toxic cause of ill health in Gulf veterans.

Vaccination emerged as a concern of ill Gulf veterans early on. Our group did indeed find that among veterans of the Gulf War there was a specific relation between objective records of multiple vaccinations given during deployment and self-report of later ill health, although it was difficult to explain why this might be from an immunological point of view (Hotopf et al., 2000). These findings and others led to exhaustive searches for immunological abnormalities in ill Gulf veterans. In our cohort we have found evidence of aberrant cellular immune activation ten years after the conflict (Skowera et al., 2004) which can be linked to the receipt of multiple vaccines simultaneously; however, it is fair to say that these findings are not accepted by some experts, and have yet to be replicated. As it is, the epidemiological evidence suggests that, even if confirmed, this will only account for a part of the observed ill health, given that these findings relate only to the vaccination policy used by the UK Armed Forces and would not be applicable to a) other Allied Forces who did not use this regime; or b) the Danish forces who were not vaccinated against biological warfare agents.

All we know is that symptomatic personnel self-report more exposure to these environmental hazards, although the same is true of non-Gulf veterans. We also know that retrospective self-reporting of exposure to hazards encountered during a conflict is not static, and is associated with current self-rated perception of health (Wessely et al., 2003) and current PTSD symptomatology (Roemer, Litz, & Orsillo, 1997; Roemer, Litz, Orsillo, Ehlich, & Friedman, 1998).

Depleted Uranium is a heavy metal and, although weakly radioactive, the risks associated with exposure to it are more chemical than radiological. The enormous media attention that has been given to DU exposure has made it difficult to interpret studies which rely on self-report of exposure. Our work shows a discrepancy between health concern over DU and likely exposure (Greenberg, Iversen, Unwin, Hull, & Wessely, 2004). A series of studies have been conducted which examine the longitudinal health of a cohort of Gulf veterans with retained shrapnel fragments all of whom demonstrate objective evidence of exposure in the form of a persistent elevation of urine uranium 10 years+ after exposure; at this point in follow-up there does not appear to be any evidence of any increased renal or neurological abnormalities in these exposed individuals (McCall & Salama, 1998; McDiarmid, Engelhardt et al., 2004; McDiarmid et al., 2005; McDiarmid et al., 2000; McDiarmid, Squibb, & Engelhardt, 2004). It is possible that the high public and media attention given to DU may be the result of its relationship with the much more well known and feared substance uranium, as fear of radiation tops the bill in risk perception studies (Bennett, 1999; Renn, 1997a,b).

3.3. *Are they psychiatrically unwell?*

Despite subjective complaints of low mood, three quarters of ill UK Gulf veterans have no recognised psychiatric disorder (Ismail et al., 2002). There does appear to be a modest increase in defined psychiatric disorders (Baker, Mendenhall, Simbartl, Magan, & Steinberg, 1997; Ikin et al., 2004; Kang, Natelson, Mahan, Lee, & Murphy, 2003). For example, disorders such as depression, anxiety and posttraumatic stress disorder (PTSD) are more common in unwell and symptomatic Gulf veterans (Engel, Liu, & Usano, 2000; Ford et al., 2001), but these diagnoses themselves rely on symptom-based constructs and therefore are bound to appear more common in highly symptomatic individuals. Also, just being symptomatic can cause low mood and high symptom scores correlate positively with psychological distress (Simon, VonKorff, Piccinelli, Fullerton, & Ormel, 1999). Our studies demonstrate that 3% of ill Gulf veterans fulfilled diagnostic criteria for PTSD (Ismail et al., 2002). Other studies have shown a slightly higher prevalence of PTSD (5.4% in Gulf veterans; Ikin et al., 2004) but the fact remains that, important and disabling though these conditions are, only a minority of returnees were suffering from traditional psychiatric injury directly related to their experiences in theatre.

4. How can we improve our understanding of GWI?

4.1. *Introduction to a model of illness*

Commentators have argued that understanding the sustained ill-health observed in Gulf veterans might be improved by reference to other medically unexplained symptoms and syndromes (Engel, Jaffer, Adkins, Riddle, & Gibson, 2004;

Engel, Adkins, & Cowan, 2002; Hodgson & Kipen, 1999). In the following section we introduce a framework for an understanding of Gulf War related ill-health which takes into account the unique socio-political circumstances of the war, considers individual factors which may explain why ill-health is confined to a proportion of those who served, and finally describes some generic concepts which may help us to understand what might keep people unwell.

4.2. *How did symptoms start?*

We have discussed above how particular medical counter-measures employed by the UK Armed Forces in 1991 such as multiple simultaneous vaccines may have had unexpected symptomatic side effects in some veterans (Hotopf et al., 2000), and that this may have served as an initial trigger for subsequent symptoms. The side effects may have been amplified by general stressors of war and arriving in a new and threatening theatre of war; we know that the receipt of a large number of vaccines immediately after arriving in theatre was associated with increased symptoms. But also there were specific and unique anxieties around in 1991 about the very real threat from chemical and biological weapons — such fears were the commonest concerns expressed by service personnel in theatre before the start of actual combat operations (Martin et al., 1992), and were realistic fears at that time given that the world had seen graphic evidence that Saddam Hussein had chemical agents to use. In March 1988 Iraqi aircraft shelled Halabja in Northern Iraq with chemical weapons in an attack which had left 5000 Kurds dead and 7000 injured or with long-term illnesses. During the Gulf conflict there were several thousand documented chemical alarm alerts; it is thought in retrospect that none of these were true positives, but at the time it is clear that military staff had to assume each to be genuine and had to follow protocol. It is plausible that such repeated exposure could have acted as a ‘sensitisation’ on a neural level and that physiological responses to such threats may have become conditioned in susceptible individuals. Belief that one has been exposed to chemical weapons has frequently found to be associated with the development of ill-health (Haley, 1997; Nisenbaum, Barrett, Reyes, & Reeves, 2000; Proctor et al., 1998; Stuart, Ursano, Fullerton, Norwood, & Murray, 2003; Unwin et al., 1999).

There is some evidence that such “sensitisation” may have occurred. Fiedler has shown that when ill and well Gulf veterans are given a single controlled exposure to low density diesel vapours, the ill veterans reported more of an increase in symptoms such as disorientation and dizziness, and were more likely to hyperventilate than healthy veterans. The authors suggest that perhaps one of the mechanisms that keep veterans ill in civilian life is that routine exposure to odours and other triggers associated with deployment, may re-elicite a conditioned physiological response, in individuals who have ‘learnt’ such a response from repeated exposures in theatre. Ferguson et al. confirm that there may be a role for associative memory in the triggering of medically unexplained symptoms in Gulf veterans. In their diary exercise in Gulf veterans, the intensity of odours encountered was positively associated with the severity on the same day and subsequent days’ symptoms (Ferguson, Cassaday, & Bibby, 2004).

The long build up to the period of actual combat whilst troops waited in the Gulf may have proved fertile ground for fears to grow (Marlowe, 2000). The understandable consequence of such concerns, one could postulate, may have been increased physiological arousal and increased attention when symptoms arose during and after conflict. All routine vaccinations produce transient and occasionally not so transient symptoms of malaise as does deployment in a novel and often uncomfortable theatre such as the Persian Gulf; concerns about heat, sand, and flies were also common (Marlowe, 2000; Ministry of Defence, 1991).

Finally, whilst in theatre, concerns about the safety of equipment were common. Fiedler has shown that those who experienced equipment failure in theatre which jeopardised their personal safety were more likely to report increased symptoms on return (Fiedler et al., 2000). These fears may then have been amplified by subsequent media attention (Winters et al., 2003); the media plays a particularly potent role at times when factual information is poor (Vasterman, Yzermans, & Dirkzwager, 2005).

4.3. *What happened when people returned from theatre/left the Armed Forces?*

On return home, denial of potential side effects of medical counter measures, and the clear message from the authorities that biological and chemical weapons had not been used during the war may have fostered mistrust of benign explanations, encouraged pre-occupation/anxiety about health and increased symptom focusing. In the UK, many Gulf veterans left the services precipitously after the war during a government initiative to reduce the size of the fighting force, ‘Options for Change’ (Ministry of Defence, 1991). The difficult transition to civilian life may only

serve to amplify and maintain symptoms. On leaving, many veterans were disenchanted with the way the military had handled their concerns and some harboured fears about their exposures during conflict. They may also have been worried about the changes that were happening within the institution, and shortly within their own lives. Boyd has shown that in Gulf veterans who believe that they have Gulf War Syndrome, higher symptom burden is associated with persistent feelings of mistrust of the military (Boyd et al., 2003). Many veterans lose the cohesive social networks which are easily accessed whilst still in service as they return to live with their families, and they may become isolated. Life is tough, particularly if you are symptomatic. Symptomatic Gulf veterans report greater difficulties in gaining employment once a civilian, and self report higher rates of concomitant negative life events such as changes or accidents in the family, and financial hardship (Boyd et al., 2003; Fiedler et al., 2000). As Susie Kilshaw puts it ‘there were other things happening in the lives of these men and women....that they are trying to explain’ (Kilshaw, 2006).

4.4. How are symptoms maintained?

Symptomatic UK Gulf War Veterans don’t seem to be getting better 13 years after the conflict ended. Hotopf et al. examined health and wellbeing outcomes in a large cohort of Gulf veterans and found that their measures of psychological distress, fatigue, and physical functioning had not improved over time (Hotopf et al., 2003). Why might this be?

Previous research has supported the idea that we all tend initially to look for external or environmental explanations for our bodily sensations (normalising attributions) and only if this process fails do we search for attributions internal to ourselves (somatic or psychological attributions) (Robbins & Kirmayer, 1991). So it is natural that those who became unwell with novel symptoms after Gulf service placed the locus of control externally when they came home. What are the consequences of making this attribution for symptoms when they are experienced chronically? We know from the health psychology literature that people cope with chronic ill-health much better if they view the cause of their ill-health to be controllable, stable and internal; worse health outcomes and less effective coping and help-seeking are associated with causal beliefs which are seen as stable, uncontrollable, and external to self (Roesch & Weiner, 2001; Taylor, Lichtman, & Wood, 1984; Tennen, Affleck, & Gershman, 1986). We know that those who attribute their health problems to Gulf War Syndrome are likely to be more unwell than non-GWS attributors (Chalder et al., 2001). Hunt et al. also observed that unwell veterans who endorsed illness attributions consistent with an external locus of control or a high degree of seriousness tended to have more severe symptoms and functioned less well (Hunt, Richardson, Engel, Atkins, & McFall, 2004). Recent work has also confirmed that continuing to make this attribution makes recovery less likely (Hotopf et al., 2004), presumably because individuals who make this attribution see their symptoms as indicative of ‘sinister and irreparable underlying pathology’ (Hotopf et al., 2004).

In any model of illness, regardless of aetiology, beliefs/cognitions about symptoms are crucial in understanding how ill-health is maintained. Beliefs about symptoms have consequences for all of us when we are unwell — they dictate our emotional responses and physiological responses, and perhaps most crucially, they influence how we think and what we do about our symptoms (Ewart et al., 1986; Sensky, 1997; Sensky, MacLeod, & Rigby, 1996). A recent US study has found that Gulf War veterans’ specific illness beliefs – e.g. “my symptoms are disabling” “my symptoms are getting worse” and “my symptoms require medical treatment” – are associated with increased symptom severity and reduced physical functioning in this group (Hunt et al., 2004). As with many of the other studies that inform the model, this data is based on a cross-sectional study and we cannot assume that what has been described by Hunt et al. is a causal relationship. It is equally as likely that those with more severe symptoms in the first place endorsed more negative statements about their health. Regardless of the direction of causation however, once the cycle of negative beliefs about health gains steam, symptoms are exacerbated. Such beliefs may cause ill-veterans to symptom focus, which we know from previous research increases distress (Fiedler et al., 2004; Moss-Morris & Petrie, 2003; Smith & Sullivan, 2003).

We don’t know yet what the physiological consequences of exposure to such out of the ordinary stress in theatre might have been, or indeed what longer lasting physiological consequences there might be to the generalised anxiety/fear that may chronically accompany beliefs such as those described above. However, further understanding of this in Gulf veterans will be crucial to building a model of illness. We know for example that physiological changes are important in the understanding of other complex medically unexplained syndromes such as Irritable Bowel Syndrome (Schwetz, Bradesi, & Mayer, 2004) and Chronic Fatigue Syndrome (Cleare, 2003). Chronic stress can have profound and long lasting effects on the hypothalamic-pituitary-adrenal axis (Owens & Nemeroff, 1993) and in turn on

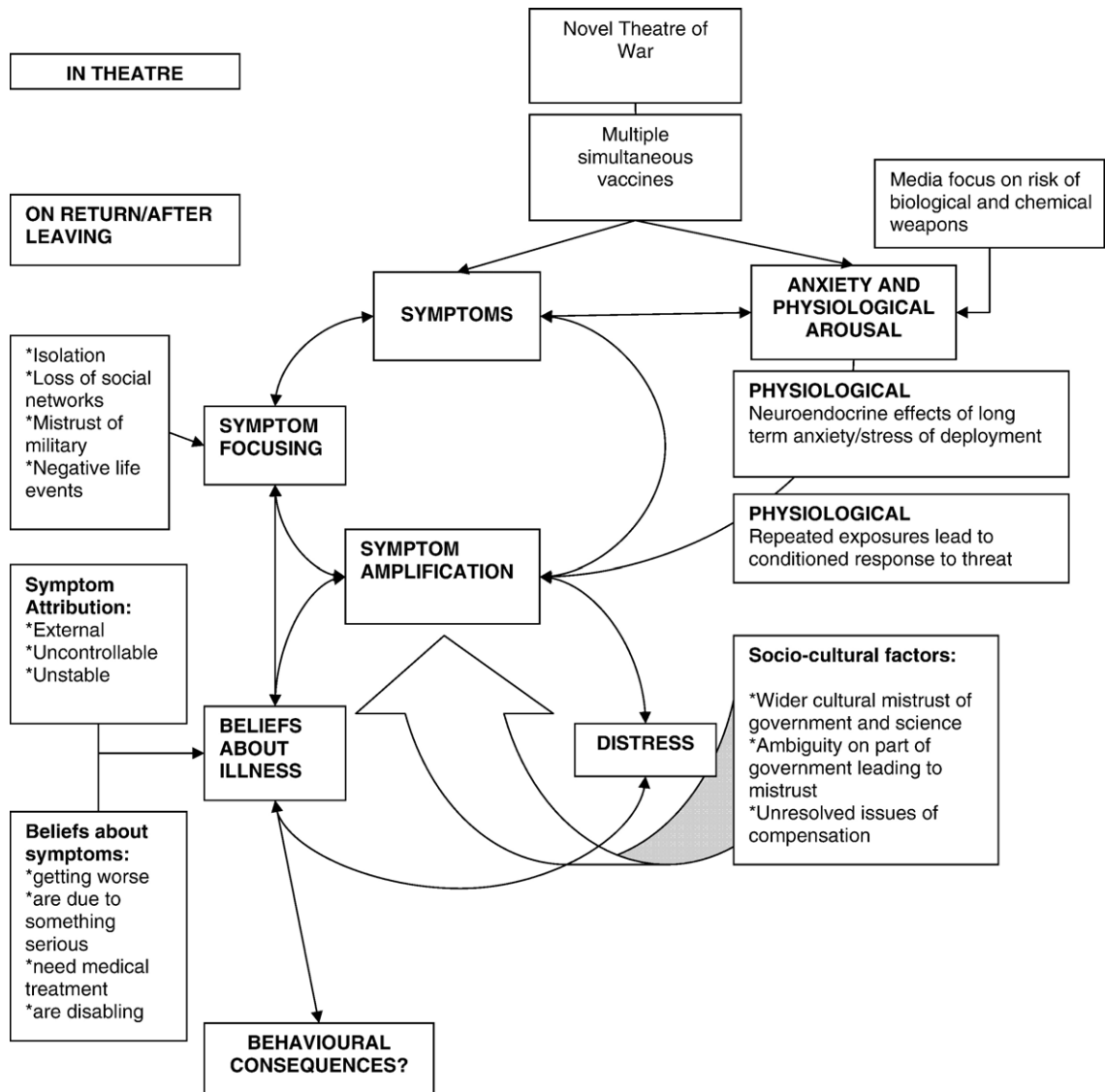


Fig. 1.

symptoms and behaviour. Further neuroendocrine research may shed light on how this might contribute to ill-health in Gulf veterans.

Finally, we should also remember that there are certain factors intrinsic to military culture which may have delayed help seeking. In the Armed Forces, personnel may develop an ambivalent attitude towards ill-health. On one hand, there is an emphasis on health and physical performance (sick parades), and staff are encouraged to consult early if they are experiencing physical symptoms which may affect their ability to function as an effective member of the fighting unit. On the other hand, personnel are encouraged to be ‘macho’ and stoical about their health and to demonstrate physical hardiness. This mixed message may leave personnel unsure about when to consult and may lead to symptom focusing and delays in seeking treatment.

All of us as health professionals are guilty of over-utilising mind–body dualism as a way of explaining the ill-health that we see, but this message may have become particularly ‘black and white’ in the tuition given to military personnel. It is our impression from anecdotal reports that fighting soldiers, particularly those of lower ranks, are often given oversimplified messages about stress physiology and the way that combat affects the body. As a consequence it may be that there is little tolerance or understanding, on the part of military patients and/or clinicians, of symptoms which do

not fit neatly into the mind or body camps. Richardson et al. have shown that military medical personnel are equally dichotomised. In their survey of staffs' beliefs about aetiology of Gulf War Illness, general internal medicine physicians were more likely to describe it as 'a mental disorder' whereas mental health physicians were more likely to view it as a 'physical disorder with a biological explanation' (Richardson et al., 2001). For many military personnel, it may be that symptoms are seen as either 'real' and having organic pathology as their cause (even if it cannot be found at first) or 'all in the mind' — which for military personnel is particularly stigmatising as it implies that they are psychiatrically unwell (Iversen et al., 2005; Rona, Jones, French, Hooper, & Wessely, 2004); it is our anecdotal impression in military culture that the term 'psychiatric ill' is synonymous with 'weak willed' for many, regardless of rank. This unhelpful polarisation is not confined to Gulf veterans themselves and their doctors, but also pervades the wider commentary on the issues by clinicians and researchers. Gulf War Syndrome is often referred to as 'a somatisation disorder' — this comparison is unhelpful as this label is almost invariably viewed as derogatory by the patient, implying somehow that the patient may not be being truthful or is unaware of the true nature of their problems (Kilshaw, 2003). Furthermore, the concept of somatisation perpetuates the 'either/or' 'organic versus psychological' dichotomy so beloved of modern biomedicine (Kirmayer, Groleau, Looper, & Dao, 2004; Kirmayer & Young, 1998; Kirmayer, Young, & Robbins, 1994).

Instead we propose there is a need to build a 'three systems model' of Gulf War Illness which takes into account cognitive, behavioural, and physiological aspects of the ill-health that Gulf veterans experience and makes a distinction between precipitating and perpetuating factors, both those that operate on an individual level and those which are unique to the Gulf deployment and the organisation of the military in general. A schematic representation of the model is shown in Fig. 1. Below we also consider some of the social and cultural reasons that may have perpetuated ill health in this group.

4.5. *The role of the cultural zeitgeist, the media and politicians*

Historical analysis suggests that medically unexplained symptomatic distress is not new and has been seen in virtually all previous conflicts of recent history (Hyams, Wignall, & Roswell, 1997) (Jones et al., 2002) (Jones & Wessely, 2004). What does change over time and with changes in culture, are the explanations attributed to these symptoms by both returning combatants and their doctors. The shape that Gulf related ill-health assumed reflects powerful cultural themes which were also being played out in wider civilian culture at the same time. Vaccinations were (and are) widely mistrusted as the concern over the MMR vaccine has demonstrated. Ever since Rachel Carson's seminal book "Silent Spring" exposing the environmental and health hazards associated with the use of Dichloro-Diphenyl-Trichloroethane (DDT) was published in 1962, concern over the use of pesticides has grown incrementally. Insights into Gulf War Illness and other contemporary unexplained syndromes can come from comparisons with other 'illnesses of modernity' (Petrie & Wessely, 2002).

Another factor which may play a role in keeping people unwell is the continued high-profile political and media debate which repeatedly highlights the ongoing uncertainty surrounding the illness. The current position in the UK shows how ambiguity about a diagnosis can help to perpetuate disability. The Ministry of Defence refuses to acknowledge that a distinct Gulf War Syndrome exists; although they do acknowledge, perhaps belatedly, increased ill-health in a proportion of those who served in the Gulf. At the present time 2885 Gulf veterans have been successful in their applications for compensation. Despite this, the Ministry of Defence make it clear that this does not amount to an admission of the existence of the disease saying '*War Pensions are awarded not for a list of disorders but for any disablement which can be accepted as caused or made worse by Service, whatever that disablement is called. The question of whether or not there is such a thing as "Gulf War Syndrome" is not therefore relevant from the point of view of War pensions*'.

The UK government has repeatedly turned down Gulf veteran lobby groups' requests for a public enquiry. In the meantime however, an anonymously funded public enquiry took place in 2005 in the UK headed by an eminent retired Law Lord (the closest UK equivalent to a Supreme Court Judge in the USA), the Rt. Hon Lord Lloyd of Berwick (The Rt. Hon Lord Lloyd of Berwick, 2005). It generated a great deal of media interest, and a large body of the report is given over to testimonials from disabled and unwell Gulf veterans themselves. The conclusions of the Lloyd report as regards the science/cause of GWS were ambiguous, but despite that there was a strong call to both accept the term "Gulf War Syndrome" and to give ex-gratia payments to sufferers, even in the absence of a reliable definition as to what this meant. The UK government has accepted the former, but not the latter. In 2005, the Ministry of Defence finally

accepted the term Gulf War Syndrome but only as a portmanteau term — not as a distinct clinical syndrome, in effect accepting a *fait accompli*.

Clearly both the science and the politics of Gulf War Illness remain ambiguous and controversial. As in other modern health controversies and/or contested diagnoses (Zavestoski et al., 2004), the result is that sufferers are forced to enter the realms of politics as patient activists and political lobbyists in order to gain legitimacy for their symptoms. As the science is inconclusive, the main evidence that a sufferer has is their own subjective ill health. As Norton Hadler memorably wrote in the context of another controversial and ill defined syndrome (fibromyalgia), “if you have to prove you are ill, you can’t get well” (Hadler, 1996). There are direct parallels here with the lobby groups post-Vietnam who campaigned for the US government to recognise the health effects of Agent Orange (Zavestoski et al., 2004). Governments on both sides of the Atlantic have also made mistakes in their handling of scientific questions relating to Gulf health issues. Whilst the most likely explanation for these errors is bureaucratic failure in understanding complex scientific issues and the sheer size of the paperwork, others have claimed more sinister motives.

Finally, it is interesting to note that with the exception of oil-well fire smoke, all the toxic hazards which have generated the most concern for Gulf veterans are ‘own-side’ toxic hazards analogous to ‘friendly fire’. The medical counter-measures were handed out to troops by their own commanders; the DU munition came from US or UK militaries; the vaccinations and organo-phosphates were used by Allied Forces to protect their troops against disease and vectors of disease and so on. Kilshaw suggests that it is perhaps easier to tolerate uncertain risks during war if they are not seen to be acts of commission or omission by one’s ‘own side’ (Kilshaw, 2004).

4.6. *The way forward*

In 2003 the Medical Research Council in the UK reviewed the scientific findings to date in the UK (in the context of the international literature) and recommended that, rather than continue the exhaustive search for an elusive aetiological factor, research should focus on interventions aimed at ‘improving the long-term health of Gulf veterans with persistent symptoms’ (Medical Research Council, 2003).

In 2003, The US Department of Defence and the Veteran’s Administration carried out a large and impressively conducted randomised controlled trial comparing cognitive behavioural therapy, graded exercise therapy and the combination of both (Donta et al., 2003); the first trial of an intervention for symptomatic Gulf veterans. Including 1092 participants at 20 sites, at a cost of more than \$10 million, it was one of the largest trials of a psychotherapeutic intervention ever published. However, the results were only modest. Several reasons have been suggested for this (Hotopf, 2003), but principally it has been argued that the treatment model was lifted directly from models developed on the basis of studies of civilians with unexplained symptoms and syndromes, principally CFS (Surawy, Hackmann, Hawton, & Sharpe, 1995). Although pilots of the treatment were conducted (Engel, Liu, Clymer et al., 2000), one of the criticisms of the VA/DOD trial was that insufficient preliminary work was conducted to determine if such models could be applied to the veteran population. It is possible that, for example, views on exercise and exercise avoidance are different for the military who tend to be fit. This is supported by our own finding that despite the high levels of symptoms and impaired health perception reported in UK Gulf veterans (Unwin et al., 1999), physical functioning as measured by the SF-36 (Ware, Kosinski, & Keller, 1994) was surprisingly well preserved, with only small differences between Gulf and Bosnia veterans.

Indeed one of the biggest gaps in our current model of illness is the behavioural consequences of believing that one’s illness is the result of Gulf service. It may be that exercise avoidance which is targeted by graded exercise therapy is less of an option for military personnel for whom daily exercise is part of routine life. If exercise is not avoided, are there other avoidance behaviours that we haven’t understood yet which contribute to ill health in this group? Whilst it is seductive to extrapolate treatment models from the existing extensive experience base of treating CFS, the above experience demonstrates that what is needed before another trial is a series of studies to better understand the particular needs of this group. In this way a model specific to the special circumstances of Gulf veterans can be developed.

Despite extensive epidemiological work, very little qualitative work has yet been undertaken or published in the field of GWS. Qualitative studies/clinical needs assessment have been used to good effect previously in the understanding of and model building for complex diseases such as Chronic Fatigue Syndrome (Surawy et al., 1995). It is perhaps this methodology more than any other that is now needed to understand the needs of this particular group. Qualitative methodology could potentially illuminate a variety of areas: the individual’s model and understanding of their illness, their beliefs and attributions about causation and maintenance of symptoms, the impact of symptoms on

the individual's functioning (including gender roles, work, relationships within the family, marital and sexual functioning, private leisure activities, physical functioning and fitness, body image), and what veterans themselves think they need and find acceptable in terms of treatment. It is a mistake for example to assume that interventions that are acceptable to civilians are *ipso facto* acceptable to ex military populations, who may still have strong allegiances to military culture with all that implies. Exploratory interviews will also allow further exploration of the models of illness which are described above; much in the way that in depth clinical interviews would be used to explore and validate any new cognitive behavioural model of psychological ill-health. Current military health study programs undertaken by our group into the health of service personnel who took part in the 2003 invasion and subsequent occupation of Iraq include substantial qualitative components embedded into the health assessments done at the time of deployment. We hope that the experiences that we have documented will allow us to understand better the reactions of individuals to the extraordinary life event of war, in order that we may be able to better meet their health needs on their return and in the future.

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