

SUSIE KILSHAW

# IMPOTENT WARRIORS

Gulf War Syndrome,  
Vulnerability and Masculinity





## Impotent Warriors



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## GULF WAR SYNDROME, VULNERABILITY AND MASCULINITY

Susie Kilshaw



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# CONTENTS

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List of Abbreviations	vii	
Acknowledgements	xiii	
Introduction	1	
<b>PART I</b>	<b>GWS EXPLANATORY MODELS</b>	
<b>Chapter 1</b>	<b>“Desert Rats, Not Lab Rats”</b>	<b>17</b>
	Introduction	17
	Biomedical Position on GWS	19
	A Veteran’s View	20
	Discussion of GWS Causes	24
	Risk	39
	Conclusions	42
<b>Chapter 2</b>	<b>Chains of Causation, Chains of Knowledge</b>	<b>43</b>
	Introduction	43
	Contested Knowledge	43
	Claims to Truth and Knowledge	51
	Levels of Causation	55
	Meta-narrative	60
	Conclusions	61
<b>PART II</b>	<b>BODIES AND BOUNDARIES</b>	
<b>Chapter 3</b>	<b>Leaky Bodies</b>	<b>65</b>
	Introduction	65
	Body Substances	67
	Body Substances as Commodity	77
	Visibility	79
	Shifting Boundaries	81
	Extended Boundaries	82
	Leaky Bodies	83
	Internal Risks	87
	Conclusions	90

<b>Chapter 4</b>	<b>“We are the Enemy”</b>	<b>93</b>
	Boundaries and Borders	94
	Theories of Causation and the Immune System	97
	Military Metaphors	115
	Conclusions	120
<b>PART III</b>	<b>GWS AS UNIQUE ILLNESS</b>	
<b>Chapter 5</b>	<b>Veterans’ Associations*</b>	<b>125</b>
	The Construction of GWS Narratives	126
	The Role of Women	139
	“You Aren’t Mad – It’s Chemical”	141
	Conclusions	152
<b>Chapter 6</b>	<b>The Disappearing Man: Narratives of Lost Masculinity</b>	<b>154</b>
	Semen	155
	The Soldier’s Body: The Embodiment of Masculinity	172
	GWS Bodies: The Disappearance of Masculinity	174
	“Old Women’s Diseases”	177
	Women	180
	Conclusions	181
<b>Chapter 7</b>	<b>Impotent Warriors: The Context of Narratives of Lost Masculinity</b>	<b>183</b>
	Military Masculinity	184
	Masculinity under Threat	188
	Gender Anxiety	196
	Leaving the Military	198
	The Military Context	201
	Conclusions: Embodying Male Lack	206
<b>Conclusion</b>	<b>GWS and World Trade Centre Syndrome</b>	<b>208</b>
	GWS: An Illness of Our Time?	208
	Risk and Vulnerability	211
	The medicalisation of Life	216
	The Approach of Anthropology	217
	Ethical Issues and Dilemmas	222
	Conclusions	227
	Appendices	229
	Bibliography	235
	Index	253

\*This chapter is not available in the open access edition due to rights restrictions. It is accessible in the print edition, spanning pages 125–153.



# LIST OF ABBREVIATIONS

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**AGM** Annual General Meeting and Respite Week

Here referring to the annual meeting of the GWVA, which provides an opportunity for members to meet, socialise and share information about GWS and the illness movement.

**BATS** Biological Agent Treatment Set

Preventative medication issued in the event of an attack by a biological weapon. Although it has been widely stated that no UK troops took BATS, a few veterans claim to have taken them.

**BFT** Basic Fitness Test

Physical fitness is a major aspect of military life and is constantly assessed. This test is the fundamental measure of fitness and must be passed by all recruits before they are accepted into the forces. All soldiers must also pass this test yearly. The test is designed to test aerobic power and muscular endurance. It comprises a 1.5 mile run, press-ups and sit-ups, all against the clock.

**BSS** Burning Semen Syndrome

The experience reported by some veterans and their wives where their semen is described as burning (causing a rash) the woman when it comes in contact with her skin.

**CFS** Chronic Fatigue Syndrome

A chronic disorder of unknown cause characterised by fatigue, pain and cognitive disorders. Debilitating fatigue is the main symptom and the cause remains unknown.

**DoD** The US Department of Defence

**DU** Depleted Uranium

Used in projectiles and tank armour and/or organophosphate insecticides.

**FM** Fibromyalgia

A systemic condition of generalised pain, often with other associated symptoms, such as sleep disturbance, irritable bowel syndrome and chronic fatigue. The defining symptoms of fibromyalgia are chronic, widespread pain and tenderness to light touch. Veterans often use this term to describe joint and muscle pain.

**FSS** Functional Somatic Syndromes

A number of illnesses that cannot be identified by physical signs, whose scientific status and medical basis remain unclear. This group of illnesses include: ME/CFS, total allergy syndrome, MCS, food hypersensitivity, GWS, fibromyalgia and sick building syndrome.

**GVMAP or MAP** Gulf Veterans' Medical Assessment Programme

Part of St Thomas' Hospital, London; the GVMAP was established in 1993 by the MoD in response to the non-specific symptoms popularly termed GWS, in order to respond to veterans' health complaints. Any Gulf veteran is entitled to attend, whereupon they are interviewed about Gulf War exposures, health concerns and any other relevant issues. They are subjected to a full physical examination by one of the clinicians and given a battery of tests (see Appendix Three).

**GWS** Gulf War Syndrome

The term used to describe illnesses and symptoms experienced by veterans of the 1991 Gulf War. It is the popular term used by veterans, reflecting their belief that their illness is a unique organic condition caused by Gulf War exposures.

**GWVA** The Gulf War Veterans' Association<sup>1</sup>

One of the main Gulf veterans' association in the UK; it is seen as more controversial than the others.

**IBS** Irritable Bowel Syndrome

An illness characterised by recurrent abdominal pain and diarrhoea, sometimes alternating with periods of constipation.

**MCS** Multiple Chemical Sensitivity

A multi-system illness resulting from contact with, or proximity to, a variety of substances. Sufferers often report a sensitivity to certain chemicals and other substances such as petrol, smoke, pollen and pet fur.

1. This is a pseudonym.

**ME** Myalgic encephalomyelitis

The name given to an epidemic which occurred among the staff of the Royal Free Hospital in London in 1955. The conclusion was that the illness – characterised by headaches, malaise, dizziness, nausea and limb pain – was caused by a virus. This name has continued to be used for post-viral fatigue and is another term, more popular in the UK, for CFS.

**MoD** Ministry of Defence

The overarching body that is in charge of the UK armed forces.

**MUPS** Medically Unexplained Physical Symptoms

Symptoms reported by a patient that cannot be linked to an organic cause.

**NAPS** Nerve Agent Pre-treatment Tablets

The drugs issued for troops as protection against organophosphate-based nerve agents. Also known by the active ingredient in NAPS: Pyridostigmine bromide (PB).

**NBC Suit** Nuclear, Biological and Chemical Suit

The full-body suits used for protection against possible nuclear, biological or chemical attacks. The suits were often donned due to a perceived threat. Also called a “Noddy suit”.

**NCO** Non-commissioned Officer

Military ranks above Private, but below Lieutenant. An enlisted member of the armed forces appointed to a rank conferring leadership over other enlisted personnel, but who is not an officer. They are the junior management of the military. In the British Armed Forces, NCOs are divided into two categories: Junior NCOs (lance corporals, corporals and lance sergeants) and Senior NCOs (sergeants, staff sergeants and colour sergeants).

**Non-deployed Veteran**

A veteran who was serving at the time of the Gulf War, but was not sent to the Gulf. Some of these veterans claim to have GWS, believing that they were made ill because of contact with Gulf War exposures. Some say they were inoculated in preparation for war and others suggest they came in contact with substances like depleted uranium when they worked on returning machinery.

**OPs** Organophosphates

A family of chemicals that affect nerve signal transmission by a molecule called N-acetylcholine, which operates throughout the nervous system in many species. OPs have toxic effects due to their capacity to bind to and inhibit the enzyme acetylcholinesterase (ACE). OPs that block insect ACEs but have a lesser effect in humans are used in pesticides. Those that affect humans have been developed as nerve gasses.

**Options for Change**

The move to downsize the military which occurred soon after the Gulf War. This course of action involved redundancies and contracting some duties out to civilians.

**PB** Pyridostigmine bromide

The active ingredient in NAPS; a drug that acts on the nervous system. It has been routinely used to treat *myasthenia gravis*, a disease of nerve/muscle junctions.

**PTI** Physical Training Instructor

Individuals in the military whose role is to train soldiers in physical exercise and fitness.

**PTSD** Post-traumatic Stress Disorder

Often confused with GWS, but a different condition. A psychiatric condition codified in DSM-III in 1980 which is thought to be the product of indelible traumatic memory. Symptoms include flashbacks, difficulty in sleeping, nightmares, hypervigilance, avoidance phenomena, memory problems and concentration difficulties.

**RAMC** Royal Army Medical Corps

The regiment (part of the larger Army Medical Services) whose role is to promote effective medical services for the Army. Part of its role is to contribute to the fighting strength of the Army. It is responsible for the evacuation and treatment of the sick and wounded in war.

**RBL** Royal British Legion

The largest and best-known veterans' association. Although they have been involved in the GWS discussion, they do not specifically focus on the illness. The RBL maintains an interest in GWS and hosts quarterly meetings: "The RBL Gulf Group Meeting" brings together veterans, scientists, doctors, MPs and advocates. During my fieldwork the RBL

also organised and hosted a two-day US Congressional meeting at the House of Lords to discuss GWS and raise the profile of the illness.

**Squaddie**

UK slang for a low-ranking soldier.

**TA** Territorial Army

A part-time volunteer reserve force. These soldiers often have other careers and are required to commit to 30 days: usually one evening a week, one weekend a month and two weeks a year.



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## INTRODUCTION

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In June 1993 the UK television programme *Newsnight* featured a story about American soldiers who had fought in the Gulf War, soldiers who were now reporting a plethora of mysterious ailments. Fatigue, diarrhoea, hair loss and cancer were some of the reported symptoms, but the list included more unusual things like vomit that glowed in the dark and semen that burned. Formerly strong, fit and healthy soldiers were becoming weak and frail. The story spread through the UK Gulf veteran community like wildfire: suddenly the malaise that they had been silently experiencing had a name. They were not alone and they were not going mad, as many of them had suspected they were. For months many veterans had struggled to understand what was happening to them: why was it that they were so tired, so irritable, so unable to cope? Many were experiencing symptoms and illnesses that they found difficult to explain. Now they had a name for what ailed them: Gulf War Syndrome (GWS).

There was a flurry of media reporting which followed the *Newsnight* broadcast as more and more UK veterans came forward to report their particular symptoms and experiences. Many Gulf veterans became convinced they were suffering from a unique and new disorder which was attributed to: exposure to chemical warfare agents, vaccinations, NAPS (Nerve Agent Pre-treatment Sets) tablets, toxic fumes from burning oil wells, depleted uranium (DU) used in projectiles and tank armour and/or organophosphate insecticides. The story was a good one, as far as the media were concerned: healthy soldiers sent to war to fight for their country and defend Kuwait from the evil clutches of Saddam Hussein only to return ill and suffering. Not only were these soldiers ill in an inexplicable way, what was even more shocking was that it was widely suggested that it was not the enemy, but their own government who were responsible for their plight: a government that was refusing to listen to them or accept any responsibility for the illness. Even more compelling was the story that children were now being born to these soldiers with horrific birth defects.

It had all the components of a modern-day tragedy. However shocking and upsetting the thought was that the government could be negligent in giving potentially dangerous vaccines and medications to their soldiers – or worse, that they did it on purpose as a vast medical experiment – it remained a believable story. In the aftermath of mad cow disease,<sup>1</sup> the debate over GM (genetically modified) foods and in the climate that led to the MMR (Measles, Mumps and Rubella) scare, there is widespread distrust of the government and in science and medicine. Scientists themselves are seen as the purveyors of anxiety and risk. Science seems uncertain: you can always find one study to support or dismiss a claim to truth. With this decline in the authority of science comes the decreased authority of doctors. Individuals now are more likely to question and mistrust their doctors. They diagnose themselves, often with the help of a media story, the Internet and/or friends. People feel vulnerable and this is felt bodily. Our immune systems, the key to our health and well-being, are constantly challenged by the increasingly toxic world. It is in this climate that GWS emerged: a story about soldiers becoming ill, their immune systems damaged, as the result of vaccines or toxins administered by a guilty government. It is a story of conspiracy, of secret chemicals and dangerous medicines. There are heroes pitted against villains and innocent children wronged. The story of GWS even has an evil dictator with his hand on the button, ready to destroy the world with chemical and biological weapons.

From September 1990 to June 1991, the UK deployed 53,462 military personnel in the Gulf War (Coker et al. 1999). Results clearly show that a proportion of individuals who served in the Gulf feel their health to be ‘significantly worse than comparable military personnel’ (Unwin et al. 1999). In 1998, 17 per cent believed they have something specific called ‘Gulf War Syndrome’ (Chalder et al. 2001). There is no disputing the fact that many Gulf veterans are ill and yet the reasons for this suffering remain unclear. There is a vast body of literature about the health of Gulf War troops, but very little include sufferer’s accounts. Medical and epidemiological studies have gone as far as they could in explaining GWS; this book argues that a new perspective is vital. An anthropological approach is needed to better understand how sufferers perceive and live with this illness. By looking at the various narratives that surround GWS, through analysing the comments and views given by veterans, insight will be gained into the cultural, social and psychological dimensions of the construction of the illness and into the ways in which this has influenced sufferers’ understandings.

1. Bovine spongiform encephalopathy (BSE)

The GWS debate quickly became polarised, with various parties holding differing views about the question of its existence. At the heart of this discussion was the authenticity of GWS as a unique, physical condition. Despite veterans' conviction of the organic nature of their illness and the media's support, medical investigations produced no compelling evidence of a physical syndrome. Studies showed that veterans did not have increased rates of mortality, that there was no single cause and no distinct set of symptoms, suggesting that there was no specific syndrome (Gray and Kang 2006; Ismail and Lewis 2006). The suggestion is that this pattern of ill health is not unique to Gulf veterans. The consensus of the international scientific and medical community is that there is insufficient evidence to enable this ill health to be characterised as a unique illness or syndrome. Thus, the MoD, the government and medical institutions do not recognise "Gulf War Syndrome" as a medical condition. In this book I argue that biomedicine has a rigid, limited view of illness and suffering that is unhelpful and often obscures our understanding of illnesses such as GWS, thereby preventing therapy and recovery. Central to this inadequate standpoint is the dichotomy within biomedicine that sees illness as either physical or psychological.

There is no doubt that GWS has striking similarities to illnesses seen in other postcombat situations (Jones and Wessely 2004, 2005). The same symptoms are seen in UK military personnel who did not deploy to the Gulf as well as in the wider population. What is clear, however, is that soldiers who were involved in the Gulf conflict report more symptoms than comparable military cohorts. Indeed, I found that any symptom, illness or problem could be considered by veterans and/or their supporters as an indicator of GWS (Appendix I and II). The range of symptoms presented by sufferers is vast, but the most common are chronic fatigue, joint and muscle pain, problems with memory and concentration, stomach and bowel problems, and loss of sexual drive. There is considerable overlap with other new illnesses found in the general population, such as Chronic Fatigue Syndrome (CFS) and Irritable Bowel Syndrome (IBS), with veterans often suggesting that these illnesses are part of their overall condition. The biomedical community has focused on the similarity between GWS and these other illnesses, which are labelled functional somatic syndromes or medically unexplained syndromes, and are defined as physical syndromes without an organic disease explanation, demonstrable structural changes or established biochemical abnormalities. As no physical cause can be found, these conditions are often seen as somatising conditions: the expression of psychological problems through bodily complaints.

I suggest that the medical community's position on GWS as part of a larger group of psychosomatic, somatising conditions is both limited and flawed. Whereas biomedical interpretations of somatisation often rest on the presumption that it is an expression of psychiatric disturbance, anthropologists have shown that it need not be limited to expressions of psychiatric distress (ie see Kirmayer and Young 1988; Kleinman and Kleinman 1985). There are a number of problems with the medical interpretation of GWS and other contested illnesses. Somatisation is used as though it is an explanation in and of itself and often represents the end of the search for explanation. Concluding that this illness is a form of somatisation is simply not good enough. Instead, one must go further and investigate the symptoms themselves and the specific composition of the illness: the way in which GWS is an expression of particular beliefs and experiences. GWS is not the bodily expression of a psychological problem. Instead, it is a complicated manifestation which reveals the way illness is a combination and intertwining of natural, biological, social, cultural and psychological factors.

We all express ourselves through our bodies and somatic symptoms. This need not be limited to the expression of suffering, but can also be a way to comment upon social or individual dilemmas or merely to convey experience. Somatic symptoms are the most common individual expression of social problems and emotional distress (Kirmayer and Young 1988) and are referred to as 'idioms of distress' (Nichter 1981; Kirmayer 1996). Idioms of distress are culturally understood ways of communicating. They are commonly experienced symptoms or problems that are recognised within the culture as indicating personal or social difficulties (Nichter 1981), yet may not be related to psychological problems. Symptoms are used to talk about and negotiate matters other than bodily illness (Kirmayer 1996).

I would agree that GWS shares many features with other medically unexplained syndromes, making it necessary to see it as part of a broader family of contemporary disorders. The cultural influences that shaped GWS are the same forces that helped to construct illnesses such as CFS, IBS and Multiple Chemical Sensitivity (MCS) and, thus, their similarities are deeply relevant. Just as GWS can be seen as part of a larger family of new and contested illnesses, it should also be understood against the backdrop of increasing anxiety about health in the present cultural milieu. Health scares, spurned on by media attention, provide a constant backdrop to twenty-first century Euro-American life. We live in a society perpetually fearful of toxins, allergens, chemicals and viruses that are seen as constant threats to health (Chapters 1, 2 and 3), mainly via their effect on the immune

system (Chapter 4). Part I and Part II focus on GWS explanatory models and theories of causation and the way in which these resonate with more widespread cultural health beliefs and anxieties.

Although it is necessary to contextualise GWS by situating it amongst other new illnesses and widespread health beliefs, there is a need to bring back the particular. I argue that lumping these conditions together as manifestations of the same thing disregards the uniqueness of these illnesses. Biomedical analysis ignores the differences between these very diverse illnesses and by so doing lacks a real understanding of the conditions themselves and the unique factors which gave rise to them. In order to balance this generalising trend, Part III focuses on the symptoms and themes that make GWS a unique condition.

In this book I draw attention to the more collective aspect of symptom and symptom language. Central to this is the way that, as an anthropologist, I look at and interpret individual symptom reporting differently to researchers from other disciplines. Illness symptoms are not only 'biological entities', but can also be conceptualised as a form of communication whereby the individual, having troubles in various areas of life, conveys these in bodily terms (Scheper-Hughes and Lock 1986: 138–39). That is to say, physical symptoms can be seen as part of a process of making meaning out of experience. Of central importance is understanding what symptom reporting is conveying, rather than focusing on uncovering the objective truth of them. Burning Semen Syndrome, impotence and infertility have all become entwined with GWS narratives and become powerful markers of it (Chapter 6) and, thus, are clearly communicating something meaningful (Chapter 7), yet these symptoms are unlikely to be picked up by epidemiological and medical inquiry. The body is a site of angst and resistance. I argue that GWS can be interpreted as the expression of a collective social angst and is a kind of shared bodily language, an expression of social distress as well as a form of commentary. This book seeks to make sense of the cultural circumstances, specific and general, which gave rise to the illness.

By enlisting the methods and theories of anthropology, with its focus on nuances and subtleties, this book provides an additional interpretation of GWS. Between September 2001 and November 2002 I conducted fieldwork amongst the UK GWS community.<sup>2</sup> During this time I interviewed those involved in the GWS movement: core activists, Gulf War veterans and their family members, as well as

2. I also conducted a small amount of fieldwork into the Canadian GWS community during a short visit to Ottawa.

doctors and scientists. My main focus, however, was on the sufferers themselves and what they had to say about their illness. I conducted 93 interviews,<sup>3</sup> 67 of which were with UK Gulf veterans – the vast majority of whom described themselves as GWS sufferers. In addition to interviews,<sup>4</sup> contact was maintained with informants to allow for more informal discussions and observations. The veterans were very welcoming and a small number of them were kind enough to allow me to stay with them in their homes. I also spent five days at one of the associations' Annual General Meeting and Respite week, where I met with many GWS sufferers and advocates.<sup>5</sup> These and other interactions, such as attending meetings, enabled me to immerse myself in the GWS community.

Aware that theories of GWS are constantly being negotiated and altered as new research emerges, I am interested in the way in which some information is accepted in some circles whilst completely dismissed in others. It is clear that GWS is being constructed and framed differently by different groups and that this process is ongoing. In order to explore the construction of GWS more fully and assess if, and how, knowledge, information, practices and language concerning GWS are mediated, appropriated and transformed, I planned to include selected non-medical sites, namely veterans' organisations. Although there are a number of associations, I focused on one in order to better contextualise the narrative on a smaller level. Also interested in the way GWS was being constructed in the medical and government settings, I conducted fieldwork at the Gulf Veterans' Medical

3. Other formal interviews included: eight Canadian veterans, four partners (not including those who were part of the research in a more informal way), fourteen non-soldier "experts"/advocates, and three focus groups, which were conducted with groups of veterans.
4. Most were one-off interviews conducted in the home of the veteran. An interview schedule was used to prompt respondents, who were asked a series of questions regarding their experiences with GWS and other health beliefs. Questions were broad, designed to provide respondents with space to describe their experiences, beliefs and assumptions. Informants were also asked to discuss their military and employment background. The interviews ranged from two to four hours and were audiotaped and transcribed at a later date.
5. The majority of informants were members of the veterans' association and were contacted through the organisation; others were accessed by other means: the MoD website and newsletter, Soldier magazine, and other veterans' associations. In order to find a wider selection of informants, the GVMAP selected 39 patients: 13 of whom were not ill; 13 who were ill, but did not attribute their illness to GWS and 13 who were suffering from GWS. The clinician wrote to them informing them of my work and asking if they would be willing to be interviewed. Of those contacted, 21 responded (20 agreed to be interviewed one declined). Four could not arrange interviews for various reasons and, thus, 16 were interviewed.

Assessment Programme (GVMAP), based in the Baird Health Centre at St Thomas' Hospital.<sup>6</sup> I hoped this would enable me to observe the cultural parameters along which medical narratives of GWS were being negotiated. It soon became clear that fieldwork does not always follow a plan and that GWS moves through arenas and society in a fluid way. So instead of focusing on sites, I studied the phenomenon of GWS in a variety of settings by following GWS itself into a variety of contexts in which it was being discussed. A methodological design is thus used which works across 'texts, practices and contexts' (Franklin 1998: 5). This type of approach is perhaps best exemplified in Martin's study of the notion of 'immunity' in America that links seemingly disparate field sites and research tools (1994).

Established in 1993, the GVMAP is run by the MoD in response to veterans' health complaints. Veterans are subjected to a full physical examination by one of the two consultant physicians and given a battery of tests (see Appendix Three). The GVMAP became the arena in which I observed the dialogue between sufferers and medical practitioners and the way in which GWS has been constructed, in part, out of this dialogue. This setting provided me with a way to observe the MoD and official medical position on GWS. When a veteran came into the centre to be assessed he or she would be asked by the clinician if they would be willing for me to sit in on the session. If they agreed, I would observe the entire assessment and often discuss the case briefly with the clinician at the close of the interview: 18 assessments were observed in this way. I also spent time at the GVMAP chatting informally with the people who worked there.

In exploring the arenas GWS inhabited, I attended a number of pension tribunals and large events such as meetings and conferences,

6. My funding from and endorsement by the MoD made some fieldwork opportunities, such as this contact with the GVMAP, possible. However, the funding opportunities offered to me also produced ethical dilemmas. As I was part-funded by the ESRC, the MoD and the Canadian Department of National Defence, I was concerned I could be seen as being biased in my research by the veterans and others. It was my opinion that the only way to tackle this issue was by being as transparent as possible. As I was offered funding before my fieldwork was underway I was able to approach the leaders of the veterans' associations, with whom I had already made contact, to see if they would still be prepared to co-operate with my research if I were to accept the funding. I made it clear to them that although I would be funded by these bodies, I would be free from interference and would remain an independent researcher, something that I was able to establish with all funding institutions. Both associations said that they would be happy to continue participation. Although concerned with the potential problems MoD and DND funding could produce, I decided to accept their financial support and I was grateful for it.

where veterans, advocates, scientists and others were in attendance. Scientists and clinicians also acted as informants; doctors' notes, diaries, symptom lists, letters and other documents were given to me by informants and added to my body of data. Media files (print, radio and television) from the past and present were explored, given the great attention GWS has received in this medium. Thus, I drew on a variety of sources to understand the condition better: using veterans' accounts, but also enlisting other resources to build a picture of the wider world in which the veterans and those around them lived.

This book describes and reports the way in which GWS has emerged and become characterised by specific motifs. It examines how GWS is a product of the way society is organised – an artefact of the particular culture in which it emerged. Illnesses can be seen as generating their energies from already present cultural anxieties and fears of a particular group. As an anthropologist, I am describing a system of thought. As Littlewood wrote about Multiple Personality Disorder (MPD),

[W]hether at this point we read multiple personality as an idiom of distress, as a psychological defence against sexual abuse or as a creative fantasy, whether we grant it some existence as a distinct psycho-physiological entity, socially induced or requiring public acceptance to bring it into the open, its local context and meanings are significant. As Sahlins notes in a not unrelated context, cannibalism is always “symbolic” even when it is real. (Littlewood 1996: 22)

Similarly, whatever we say or believe about GWS, its context and meanings are significant. It is not the anthropologist's role to decide whether or not something is rational, it is our job to make it intelligible (Firth 1985).

Central to this discussion, however, is the concept of rationality. Overing suggests that anthropologists investigate moral universes, with their basic duty being to “understand the intentions and objectives of actors within particular social worlds, as well as what these actors say, understand, believe truth and those worlds to be, a task in metaphysical description” (1985: 4). Firth (1985) argues that it is the role of the investigator to capture both the sense and the sensibility of behaviour. The anthropologist unfolds the *intelligibility* of behaviour, and not so much its ‘rationality’. Firth shows the way in which what at first appears to be irrational behaviour takes on a different face, a blend of reason and affective reaction, when placed in context. What does seem significant is whether it is capable of being understood by an anthropologist from another cultural setting, with a curiosity to enquire after meanings (Firth 1985: 33). Following Firth, I contextualise GWS by looking at the



cultural circumstances that gave rise to it, in order to show how it makes sense.

Similarly, the philosopher/sociologist, Gellner (1974) suggests that concepts and beliefs do not exist in isolation, in texts or in individual minds, but in the life of people and societies. Context must be known. The real essence of Durkheim's doctrine, according to Gellner, is the view that concepts as opposed to sensations are only possible in a social context, and that they can only be understood when the social context is known. Context refracts the line of interpretation, but "tolerance-engendering contextual interpretation calls for caution: that as a method it can be rather more wobbly than at first appears ... [T]he prior disposition concerning what kind of interpretation one wishes to find, determines the range of context brought in" (1974: 32).

When we contextualise what people say, it makes sense. The wider we follow the phenomenon out the more sense it makes. I look at the narratives of sufferers and those around them to unravel how the illness is both a unique expression and way of making sense of the experiences of a particular group of people as well as a product of wider social issues. GWS is wider than the Gulf War; it is characteristic of the anxieties and beliefs of late twentieth-century life. There are other things happening in the lives of these men and women that they are trying to explain, and the package is unique. I examine the way in which illnesses are formed by fitting into the existing illness models. GWS emerged and gained media attention because it both responded to and conformed to existing illness beliefs and anxieties. Simultaneously, it was formed by these pre-existing cultural beliefs.

An illness movement "will take only if there is a larger social setting that will receive it" (Hacking 1995: 40). In order for an illness to gain legitimacy it must resonate with a larger cultural framework which makes it intelligible. Illness representations spread throughout a population: a sort of "epidemiology of representations", the circulation and contagion of ideas and anxieties (Sperber 1985). Hacking (1992b) points out that certain disorders result from the interaction between individuals and their cultural and medical surroundings. The individual may not be representing a mirror of society, but instead the fault lines of the culture. GWS has been constructed, framed and articulated by particular themes that are relevant to the society. This book investigates the cultural themes and anxieties that allowed GWS to emerge and, in turn, help to construct it.

Sociologists and medical anthropologists have focused on the way in which metaphor informs illness through its relationship with physical experience (Lakoff and Johnson 1980) and the way in which certain metaphors become prevalent tropes for illness (Sontag 1978; Hacking

1992a; Littlewood 1998). Our language and our very ideas about illness become so intertwined with these metaphors that we are no longer consciously aware of the meanings they convey. This will, however, impact on the way we experience our bodies and our illness. There is no “sharp distinction between metaphors, attributions and sensations; even a conventional metaphor or attribution may shape perception so that the corresponding symptom is actually felt” (Kirmayer 1996: 4).

Although Sontag felt that metaphor should be stripped away, I would maintain that one cannot easily strip away metaphorical thinking, for no one ever “experiences cancer as the uncontrolled proliferation of abnormal cells. Indeed, we can experience anything at all only through and by means of culturally constructed socially reproduced structures of metaphor and meaning” (DiGiacomo 1992: 117). As we can only experience and understand illness through these culturally constructed structures, it is pertinent that we investigate them to understand a condition such as GWS fully. It is only through analysing the use of metaphor in GWS narratives that we can reach a more complete understanding of the illness and how it is experienced. Thus, I investigate what the metaphors are that inform the language and experience of GWS – what metaphors have become embedded in the stories and accounts of the illness. Discussions of GWS incite the passions of people who, at first glance, one would not expect to have a stake in it. GWS is symbolically very juicy – a “hot” topic on which most people have a political view. The symbolic wealth of GWS is that it is about much more than itself: this book explores the way GWS has become a potent symbol and a means by which to talk about a plethora of issues, anxieties and concerns.

Sontag warns against disease being translated into metaphor, while anthropologists warn against the opposite: translating metaphors of experience into biomedical entities (Scheper-Hughes and Lock 1987). The “individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle” (Scheper-Hughes and Lock 1987: 31). Anthropologists have argued that physical bodies are shaped by culture – partly by means of widely held models, images and metaphors. Metaphor not only arises out of embodied experience but, conversely, becomes embodied. Thus, we should investigate the “psychophysiology of metaphor” (Kirmayer 1992: 226). The relationship between metaphor and illness is fluid and travels in both directions. Metaphor informs illness and certain metaphors become dominant tropes for illness., Illnesses are also metaphors of experience, though. Metaphor can be appropriated to draw attention to and comment upon a dilemma, thus

becoming a social and political critique (Scheper-Hughes and Lock 1987; Kirmayer 1992; Lock and Scheper-Hughes 1996). I will argue that GWS symptom reporting can be interpreted as a vehicle to draw attention to and a means to communicate concerns of the people it affects. These include issues such as trust, life within a dramatically changing military, gender roles and toxicity (Chapter 6 and 7). GWS is an expression, both social and personal, of the experiences of those it affects and of contemporary issues.

Illnesses can be seen as an organising feature, a way to make sense of life events and distress. In this book I show that subscribing to a diagnosis of GWS is a way to make sense of a set of experiences (Chapter 5). Through the explanation of GWS all experiences of misfortune and illness are linked together and made intelligible. Here I turn to Evans-Pritchard, for which anthropologist can think of cultural responses to misfortune without thinking of *Witchcraft, oracles and magic among the Azande* (1937 [1976])? For the Azande, immediate and natural causes were understood to cause misfortune and illness, yet there was a further aspect which answered the 'why', the reason for the association in time and space. Such an explanatory system can be seen as similar to Gulf veterans' understanding of their illness. One veteran explained to me that he walked with a walking stick because he had a bad leg. He had a bad leg because of a motorcycle accident, but he was disabled because the leg did not heal properly because of GWS. Veterans create theories of causation that help them to make sense of their world.

The special contribution that anthropology can make to the study of GWS is in seeking to contextualise and investigate what else is happening in the lives of these people, besides their malaise. Importantly, such an approach introduces elements of which sufferers might or might not be aware. Whereas medical studies of GWS focus on the individual, their body and also the narrow boundaries of their war experience, an anthropological approach widens the frame and looks at other relevant aspects of a person's life. Thus, I look at GWS within the context of veterans' lives: within the war, the military and more widely. In addition, I widen the context outwards in order to see GWS within the realm of twenty-first century health anxieties and beliefs in the UK.

Researchers investigating contested illnesses such as GWS will constantly be asked: "Does it exist?" "Is it real?" Hacking (1995) reported a similar situation when he studied multiple personality disorder (MPD). He pointed out the fallibility of the questions: a real what? Of course it is real, Hacking put forth, in that there are people who fit the criteria of MPD. Similarly, I suggest that of course GWS is real; but what is it? In his work on the creation of the category of post-

traumatic stress disorder (PTSD), the medical anthropologist Young (1995: 5), wrote:

If, as I am claiming, PTSD is a historical product, does this mean that it is not real? On the contrary, the reality of PTSD is confirmed empirically by its place in people's lives, by their experiences and convictions and by the personal and collective investments that have been made in it. My job as an ethnographer of PTSD is not to deny its reality, but to explain how it and its traumatic memory have been made real, to describe the mechanisms through which these phenomena penetrate people's life worlds, acquire facticity and shape the self-knowledge of patients, clinicians and researchers.

In the same way, this book is an attempt not to explain GWS away, but instead to provide an ethnography of the illness and the place it has in the lives of those it affects. I argue that this question of the reality of GWS is redundant: of course this illness is real in that people understand themselves to suffer from it. Being interested in the way it has been socially constructed does not mean that the illness does not exist. As Hacking (1999) suggested, social construction and reality do not seem especially at odds with one another. With this in mind I would argue that the reading of this book would not be altered if, one day, a physical cause of GWS is positively identified.

When the question of the reality of GWS is posed, it generally comes with certain connotations. Those involved are forced to take sides: either you believe it exists and all that goes with it or you are a non-believer. Either GWS is physical or it is in the veterans' minds. The world of science, and often, correspondingly, the Euro-American worldview, assumes a world of black and whites. Yet this artificial system of either A or not-A does not reflect reality, where there are not two extremes but infinite shades of grey in between (Kosko 1994). GWS discourse is polarised along two lines: there are those who think it is a unique, physical illness caused by Gulf War toxins and those who argue it is likely a psychological condition that can be seen as part of a larger group of illnesses. The debate that surrounds GWS reflects a continuing bias within biomedicine, in which illnesses are seen as either physical (more real and more worthy of attention) or psychological (more the fault of the sufferer, less real and possibly "imaginary"). Entwined in this latter perspective are notions of GWS as a form of hysteria or somatisation.

We, therefore, are left with a situation where discussions of GWS are divided along two opposing sides where any findings or suggestions put forth by one side are immediately attacked, derided or, more often, ignored by the opposing side. Because of the rigidity of medical classifications, the debate was bound to become stagnant and unhelpful. Biomedicine has too narrow a view of illness and suffering,

which makes it difficult to understand and respond to illnesses such as GWS. Seeing illness as either physical or psychological is not only reductive and unhelpful, but incorrect. Furthermore, when we medicalise we ignore the social and cultural aspects of illness, thereby losing sight of the complicated factors that not only shape, but give rise to suffering. An anthropological approach enables one to go beyond this mindset and investigate the reasons behind an illness, how it arose and what is happening in society that contributes to its development. GWS is neither physical nor psychological, but both. Moreover it is a social, cultural and personal phenomenon. GWS must be seen in context; a reading of this illness must take into account wider social issues whilst bearing in mind the subtleties that make it unique. Moving beyond the dichotomy of either physical or psychological, anthropology enables one to inhabit and explore the grey areas that illnesses such as GWS inhabit and by so doing, understand them more fully.



## **Part I**

# **GWS EXPLANATORY MODELS**





## Chapter 1

# **“DESERT RATS, NOT LAB RATS”<sup>1</sup>**

During their Annual General Meeting and Respite Week (AGM) in 2002 the members of the Gulf War Veterans’ Association (GWVA)<sup>2</sup> discussed their experiences of the war. One veteran stood up and said, “We were desert rats, not lab rats”. The room erupted in enthusiastic agreement. I was struck by this interesting analogy because it seemed to embody the veterans’ beliefs, their ongoing attachment to their identity as a soldier in the Gulf War and their unbending assertion that they had been experimented upon by their government.

### **Introduction**

Gulf veterans had a series of experiences which they make sense of in a particular way. They understand their suffering to be caused by various exposures: to vaccinations and other preventative measures, depleted uranium (DU), chemical weapons, organophosphates (OPs) and oil fires. This explanatory system is still in flux: it accommodates new findings, new scientific directions and is open to internal alterations as long as the central tenet remains intact. Information which would contradict the overall explanation – that Gulf War exposures caused a physical illness – is ignored, dismissed or altered. At times parts of theories are used whilst the other aspects are forgotten. Furthermore, theories of causation of GWS remain a watertight system

1. ‘Desert Rats’ was the nickname of the Gulf War 7th Armoured Brigade.
2. This is a pseudonym.

able to deflect criticism and accommodate a vast array of factors which, at times, appear to be contradictory. Veterans and their advocates hold together a jumble of theories, which sometime overlap, sometimes are believed simultaneously, and are often altered. This system may look confused, but it is no different from how most people make sense of the world; people pick and choose those theories available to them which best make sense of the world. It is a coherent system but it is also flexible. As Evans-Pritchard wrote of Azande witchcraft beliefs:

[T]hey are not indivisible ideational structures but are loose associations of notions. When a writer brings them together in a book and presents them as a conceptual system their insufficiencies and contradictions are at once apparent. In real life they do not function as a whole but in bits. A man in one situation utilizes what in the beliefs are convenient to him and pays no attention to other elements which he might use in different situations. Hence a single event may evoke a number of different and contradictory beliefs among different persons. (1976: 221)

The view of GWS held by the scientific community is discussed below. This is then contrasted with the veterans' view, by way of a detailed account given by one veteran and his wife. The various themes which emerge from the narrative are then analysed and supplemented with other data. Although there is a mainstream biomedical understanding of the illness, science is not homogeneous and there are scientists and doctors who dispute this construction. Veterans make use of these scientist's theories and incorporate them into their explanatory models. Whilst veterans generally ignore and dispute findings put forward by researchers who dispute GWS as an organic condition, they do incorporate those aspects which support their construction of their illness; thus, they pick and choose parts of theories. Despite denials by the scientific community of a unique GWS, public understanding of the illness is very much in line with the veterans' view. In this section we see the way people build theories to make sense of their lives. While this may not reflect a biomedical way of making sense of the world, veterans' theories remain very rooted in science and medical language. Veterans ignore, embrace, alter and accommodate various scientific findings and understandings about GWS and the world at large.

Although often presented as bizarre, illogical and incoherent, on closer inspection veterans' accounts make a great deal of sense. Their focus on dangerous exposures resonates with common cultural fears of toxins, chemicals and other invisible dangers. There is a sense that exposure implies contamination, reminiscent of Frazer's (1922) notion of contagion: that two things which have been in contact continue to

act on one another long after the physical connection has been severed. The idea that there is something inside them, that they are experiencing an interactive assault, is more than reasonable in a world where we are constantly concerned with how most things (e.g. certain foods, stress, lack of sleep, toxins) affect our immune system. These narratives sound familiar to us: they remind us of recognisable ailments. Their emphasis on the individuality of the illness – the notion that assaults affect each of us differently – echoes common-sense ideas about health and illness.

### **Biomedical Position on GWS**

The accepted biomedical understanding of GWS is that we do not have a medical explanation for it. Although it is acknowledged that some veterans of the Gulf conflict have become ill and report more ill health than comparable groups, the suggestion is that this pattern of ill health is not unique to Gulf veterans (Ismail et al. 1999; Unwin et al. 1999; Cherry et al. 2001; Gray and Kang 2006; Ismail and Lewis 2006). The same symptoms are seen in UK military personnel who did not deploy to the Gulf. However, veterans of the 1990/91 Gulf conflict report having more of the symptoms and are suffering more severely from them. It is incontrovertible that rates of ill health are greater in veterans of the Gulf War than in members of the Armed Forces who served elsewhere. This same trend has been seen in the US, Canada, the UK and Australia, but not in Saudi Arabia (Gacksetter et al. 2005). The only disease-based outcome which has been somewhat accepted in medical circles is the elevation of motor-neuron disease (MND) and yet this finding is generally seen as not definitive; Wessely and Freedman point out that this does not explain ill health in anything but a very small number of GWS sufferers (2006: 722).

Studies have found that Gulf veterans do not present a distinct and identifiable pattern of symptoms or signs. Thus, the consensus of the international scientific and medical community is that there is insufficient evidence to enable this ill health to be characterised as a unique illness or syndrome. In May 2003 the Medical Research Council (MRC) addressed this in a review of research and came to the same conclusion, arguing against classifying the condition as a unique illness. In short, findings from the scientific and medical community have led the MoD, the government and medical institutions not to recognise

“Gulf War Syndrome” as a medical condition.<sup>3</sup> Each toxic exposure and the possible “cocktail effect” have been studied in depth and dismissed as causes of GWS (see Wessely and Freedman 2006). Interestingly, the focus for both the scientific and veteran communities has remained on the exposures themselves. In 2006 and 2007 two reviews were published on GWS research to date: a special issue of *Philosophical Transactions of the Royal Society* and a book edited by Lee and Jones (2007). Both publications support (and influence) the view within biomedicine of GWS: that the illness remains medically unexplained, but that it is likely to be a psychological or social condition: that GWS is likely the result of psychosomatic or somatisation processes.

### **A Veteran’s View**

Debbie and Mark<sup>4</sup> are well known in the GWS community due to their high media profile. Mark is ill with GWS, but what is unique about his family is that his four children are also ill (see Chapter 6). After being put in touch with the family by the veterans’ association, I went to stay with them for a few days. They told me that they had become involved in the veterans’ association in 1994 after reading a story in the paper. Debbie said that before she saw the article she felt that there was something wrong with her husband but that he would not admit it. It was not until after her first two children were born, she said, that Mark began to think there might be a problem. She would notice things in Mark: he seemed to have stiff joints; and at times when she was talking

3. Recently there has been renewed interest in the classification of GWS as a medical condition as a result of the 2004 Lord Lloyd Inquiry. This inquiry, which reviewed the literature about GWS and heard testimonies from veterans and scientists, concluded that GWS should be accepted as a unique biomedical phenomenon, and called for the MoD to accept it as such. However, this has not taken place and the findings were widely criticised by the biomedical community. The medical community and the MoD argued that the inquiry, and Lord Lloyd in particular, was not in a position to make medical judgments. They also argued that the inquiry was biased and was merely reviewing the established literature rather than doing anything new.
4. All names of veterans have been changed along with other identifying features. The names of scientists and government figures, however, have not been changed. The scientists and researchers who appear in this book are well-known public figures who are linked to their published literature, making it impossible to mask their identities. For a further discussion of anonymity, claims to knowledge and ethical dilemmas posed by this work see the final chapter on “The approach of anthropology”.

to him, it seemed that he was not there. He was also irritable and "snappy". Debbie said she just had the sense that something was not right, so when she saw the story in the paper with the association's contact details, she called them.

Mark had joined the army in 1985 at the age of 16. After his initial training he became a driver who transported large machinery. He was based in Germany for three years and also did two tours of Ireland. In October 1990 he was sent to the Gulf and returned to the UK in June 1991. Soon after returning Mark began experiencing pains in his legs which made it more difficult to complete fitness tests. One month after he returned from the Gulf he met Debbie, who was also in the army. At this time Mark was having some health problems: he was spitting up blood and taking tablets for a "bad stomach". The problem now is that they do not know what was wrong with him because he cannot remember and all of his medical records have been lost. The army was changing and a lot of people were leaving the forces, so Mark decided to leave the army in 1993, as did Debbie. Mark subsequently became a lorry driver until 2000, when he stopped working.

Debbie says that their doctors do not know what is wrong with Mark and are as frustrated about it as he is. Sometimes she wonders if it was something other than the Gulf that made them all ill, but cannot think what. At times the doctors have said that her eldest son's problems are all in the child's head; the same has been said of Mark. They have a nutritionist who is interested in the Gulf War; he put them in touch with Paul Shattock, who works on diet and autism. Shattock conducted a urine test on Mark which revealed vaccine poisoning; he suggested that they get in contact with Malcolm Hooper, a leading scientist in the GWS movement who is also the veterans' scientific advisor. When asked about what caused the illness, both immediately pointed to the vaccines.

Mark has knee pain, joint pain, forgetfulness, mood swings, flashbacks, bleeding gums, ulcers, "bleeding from his backside" and he describes that frequently his "get up and go gets up and goes". He has also been diagnosed as suffering from PTSD and has been told by doctors at the GVMAP that most of his problems are "psychiatric". As Mark understands it, the doctor's diagnosis is: it is your "brain saying you have these problems but [you] don't really. It's all in your head". As Mark argues,

I don't think what you've seen would make your joints sore [...] Like we don't know what causes the Gulf war illness, but there is evidence of, um, personally I've got what's shown as massive vaccine damage in the stomach

umm, or even the back passage or oral bleeding. [1]<sup>5</sup> Those are all physical things I don't see how a psychiatric problem could cause you to bleed, you know what I mean? ... The bleeding, it's something that's there you can actually see it. The vaccine damage is there; you can see it ... But the illness itself, it was a lot of small things that you didn't really piece together. Like the joints and then being sore. [2] I thought that maybe it was because I had been in the army since I was sixteen and it was a bit too much. Umm and the fact the job did entail a lot of heavy lifting. Um, and my knee, my doctor gave me an explanation for the knee, he said the knee cap was crumbling, due to running in boots and the lifting, the heavy lifting and lifting things incorrectly and things like that. [3] Um, it wasn't really until we were out and we started meeting, I suppose it was Debbie that started to put it together first. Sort of reading about it in the newspaper and people describing their problems and you are thinking, "well I've got some of their problems as well". Not as much as what some of them have got, obviously ... and then just piece it together like that and then by talking to people as well. And Debbie, she's on the phone to people and they're describing their husbands and she's like, "You just described my husband as well." People that you don't know. It's not as though that it's a great conspiracy ... people talking to people they've never met in their lives ... and that's how you put it down. And the only thing we had in common was the fact that we'd been to the Gulf. [...] [4] I don't think anybody knows what caused it and I don't think anybody will know what caused it. And really I don't think it really matters what caused it ... It might do to the medical people and that, but I don't think it really matters. I think the main thing is that you are trying to find a way to help people that suffer from it rather than being obsessed with finding the cause. I suppose the cause [is important] for those that don't think it exists. [5] I think it's a combination of everything. [6] The fact that they gave us all these vaccinations and in such a short space of time. [7] Um and giving us unlicensed drugs as well, and the [8] NAPS: they were unlicensed and untried, untested on humans until we went to the Gulf. So really we were guinea pigs for the NAPS. [9] There's also the issue with the DU as well. We came in contact with vehicles that had been hit with DU shells. Battlefields that were covered in spent DU rounds. [10] Smoke from the oil fires as well. We were driving through those as well. When we were driving from Kuwait into Saudi Arabia. [11] You got the adrenaline pumping through your body, [12] so I think it's a combination of all that that caused it. [13] There was also a paper that came out in America that said that you were more prone to get it if you had a certain gene within your makeup as well. But I don't know if that was ever substantiated. They were trying to explain why some people suffered when other people didn't and that was one of the things they came up with. [14] I think it was a combination of all the things that were there and here at the time that possibly caused it.

5. Throughout the narrative I assign numbers to different topics. In the discussion section that follows, I refer to these topics by reference to the topic number.

During this interview with Mark, Debbie had been in the other room. At this point she came into the room and joined the conversation:

[15] Malcolm Hooper did the urine test. Mark did it and all the kids. [16] [He was the] first one to say that Michael [their son] had an allergy to dairy products. Also linked to autism. Michael is totally off dairy and noticed the difference. Coughing all the time since birth. Thought it was asthma, but it was building up phlegm. [...] [17] I think it [GWS] is something with the central nervous system and causes all these things. [...] [18] I don't know much about them [OPs]. It's something that attacks the central nervous system. Could cause Chronic Fatigue and that. So I don't really know enough about it. Do you? [to Mark, who says no]. Mark lived in his lorry, they weren't in tents or anything like that, you know what I mean ... not around a lot of it. But DU you were there, you were all over it. [...] [19] It doesn't matter what done it. If they know ... recognition [*sic*], even if they can't cure them, recognition from doctors and GPs that know that it exists. A lot of people still don't think it exists and that's the main thing. If they can't cure you if, which I don't think they can, I think the thing half way to treating the ones who get depressed and that is getting doctors to recognize it. He had one doctor that turned around and said, "what do you expect when you go to war". He was very rude. We were so angry with him we just got up and walked out. [...]

[20] I've been thinking about that lately that it might be MMR. But Michael's had it since birth, but MMR they get really young. So maybe it is. [...] Because I've been reading about it. Rebecca [leading GWVA member] told us about Dr Wakefield who looks at these things – a gastro ... is his specialty. But problems with MMR show that vaccines are a problem. But MMR helps most kids. It helps more than it hurts, so it shouldn't stop. Michael has autism, et cetera, but he also has other things. [...] [21] Our doctor told us that the children's problems are possibly due to DU; she said that their problems were the same as those found in the children of Iraq. DU causes birth defects, but other people were made ill by other things. [22] I think the concoction of the injections never helped. [23] I do think that. I don't think its one particular element of why Gulf War veterans are ill. And I think that's why it's hard to pinpoint what caused it ... [24] I think it was unique in the way that that much went on. I mean it was a rush with people getting the injections, the signals were going out and they didn't get the instructions on the DU ... Also like talk to Mark, he was in the part of the desert where the smoke was that thick and black. Because of the oil ... that had to do something ... they were out there ten months, not three weeks or six weeks. He went from October to June ... that's a long time in the desert.

## Discussion of GWS Causes

It is clear from this account that GWS systems of thought are not unitary. There are, however, a number of dominant themes which are contained in this narrative and reflect accounts of the majority of sufferers. It is extremely relevant that Mark begins his discussion of his illness and its cause by disputing the argument that it is psychological in nature (1);<sup>6</sup> the denial of psychological factors is central to GWS narratives and will be discussed fully in Chapter 5. Veterans often suggest that any psychological symptoms are chemically induced. Another typical element of their accounts is that the sufferer initially explained their problems in their own way (2), until then came across other sufferers. Through speaking with them their past experiences suddenly made sense and the link to the Gulf War was made (3). The various exposures are key to this realisation of the relevance of the Gulf War. The Gulf exposures are the starting point, the diagnosis and that which all veterans have in common. In this way, GWS is unique as it is not necessarily symptoms or clinical features which represent the diagnosis, but the cause itself.

Both Mark and his wife mention (4, 19) that discovering a cause is not important, yet focus on the causation of the illness. They discuss the difficulty in deciphering the exact cause due to the sheer number of possibilities. Although they suggest that it is unnecessary to uncover which exposure was the culprit, they do ascertain that cause may be important in terms of proving the existence of the illness. Thus, cause is tied up with truth and proof. They later told me about their anger at being told by different doctors that there was nothing wrong with Mark; that his problems were normal. One doctor took every complaint and pointed out why that was normal for someone of his age, much to Mark and Debbie's anger. They described their complete relief when Mark was told that he was ill. Although Mark and Debbie say they are not concerned about the specific causes, their focus on the various exposures suggests that it is a central issue. Indeed, for most veterans, uncovering the cause is fundamental and they see it as central to their fight for recognition.

Mark suggests that the cause of the illness is unknown, but that there are a large number of possible culprits. Veterans often list each exposure and their contact with them, sometimes going into great detail. Every exposure is a cause of anxiety because of its novelty; it is

6. Throughout this section such a number refers to the area(s) in the narrative that discuss this particular topic.



as though the modernity of the substance itself makes it an object of apprehension. Vaccines play the dominant role in theories of causation (6, 22) and veterans often point to scientific studies which suggest a link between self-reported symptoms and vaccinations (Unwin et al. 1999; Cherry et al. 2001). They disregard findings which suggest that there is little evidence of vaccination causing veterans' illnesses.<sup>7</sup> It is often pointed out that injections were the "common denominator" – the exposure which all sufferers have in common.<sup>8</sup> Vaccines are frequently referred to as the dominant, primary and original cause of the illness. Mark, like most other veterans, suggests that the large number of vaccines given over a short period of time is hazardous and likely to be a major factor in their illness. Veterans explain that the body simply could not respond to so much information. When discussing the number of vaccines and the proximity in which they were given, many veterans refer to the recent and ongoing controversy surrounding the Measles, Mumps and Rubella (MMR) vaccination. In 1998 a paper was published in the *Lancet* which suggested a link between the MMR vaccine and autism and bowel problems. This caused, and continues to cause, a huge amount of anxiety in the UK, with a large number of parents either refusing to vaccinate their children or opting for single vaccines. Many veterans believe that the alleged problems with the MMR vaccination were similar to their experience of numerous vaccinations in a short time. Veterans' theories thus absorb aspects of other topical issues. So, as the public debate about the relationship between the MMR vaccine and autism appeared, veterans drew on aspects of the theory to make sense of their own illness.

Veterans refer to the large number of vaccines as "overload" (Chapter 4) and often recount which vaccines they were administered. John, an ill veteran and one of the leading campaigners, focuses on experiences during the war to emphasise the danger of the vaccinations, noting that a number of troops became ill as a result of the vaccines and had to be sent home. The fact that a small number of

7. A number of studies have suggested that there is not a link between the vaccinations given and GWS. In 2003 a major review of all the relevant literature on GWS was undertaken by the Medical Research Council (MRC). This review concluded that there was no known link between the Gulf vaccinations and GWS. Peakman et al. (2006) have more recently suggested that there is no link between vaccines and GWS.
8. I did meet people who reported that there were those who were suffering from GWS who did not have the vaccines and did not go to the Gulf, but claimed other exposures. For example, I met one man who had GWS because he had worked on the vehicles that had come back from the Gulf that were "covered in DU dust".

veterans had adverse reactions was often used to highlight the dangers of the vaccines they were given. There was clearly anxiety at the time of immunisation. Irwin et al. (1996) remind us that when investigating public understandings of science we must remember that the public has its own knowledge already. Not only do they build on common understandings about the immune system and vaccinations, but soldiers are amongst the most vaccinated people in the world and are taught about them regularly by the military itself.

Vaccines are seen as the start of a process of deteriorating health: the injections given to soldiers made them vulnerable, and the other exposures simply added to this initial degradation of health. This theory applies well-known medical understandings of vaccinations and the immune system, which veterans then build on using their own personal experience. For example, they point out that some experienced flu-like symptoms after being vaccinated, emphasising that their immune system was diminished. As John and his friend Jack, another ill veteran, explain:

*John:* I personally believe that the vaccines and the medication we were given were the first insult to the immune system and anything else after that was secondary. And whether those people that were insulted at the time their immune system didn't recover in time to react against the organophosphate compounds that were in the air. Or indeed, DU. Maybe the younger people their immune system did recover to give them protection ... Mostly a case of exposure as well. Some people were more greatly exposed than others. And some suffered more extreme stress at the time.

*Jack:* The initial assault being the injections. We have people that were, for example, who were in Cyprus, or indeed in the UK that were given injections and were subjected to that regime because they were due to fly out. Eventually they didn't fly out and they have come down with the majority of the illnesses ... Didn't have DU or oil well fires that have come down with a lot of the problems. So, like John said earlier, a lot of people were made worse by the injections, some were made worse by the DU, some were made a bit worse by the oil well fires. If your name were lucky you got triple whammy. But certainly I think the major area to look at, again, I'm not a medic, I'm just a simple gunner, is the injections because that is the common denominator with people in UK, Germany or Cyprus that never set foot out there. [...] I think the injections were like pushing a start switch. That's started a series of events in motion, which was then further exacerbated by things in the air, by depleted uranium, by oil fires, by whatever. But I think that initial start switch, I think initially was caused by injections.

The centrality of vaccinations is key to the inclusive GWS explanatory system as it enables people who did not go to the Gulf who are ill to be included: it makes the incoherent coherent.

Central to this argument of accumulating dangers is the immune system. The role of the immune system in GWS explanatory systems will be explained in depth in Chapter 4. However, it is important to explain at this point that vaccines were seen as the initial assault on the immune system, leaving many open and vulnerable to further assaults in the form of exposures such as DU, oil fires and NAPS (Nerve Agent Pre-treatment Sets) tablets. However, although veterans believe some people could become ill because of the injections alone, most stated that they believed that those who had been to the war were more ill due to additional exposures.

Mark includes NAPS tablets as a likely causal feature of his illness and points out that they, too, were untested and unlicensed (8). Veterans are well aware of the scientific qualities of NAPS tablets, as they were described to them prior to the war: they are aware that they affect the nervous system and so develop this scientific theory to understand the cause of their illness. Debbie, for example, suggests that she thinks GWS involves the nervous system (17). When NAPS tablets are implicated in the health problems of veterans, the suggestion is that the compound has penetrated the central nervous system. If a nerve agent does not kill, it can injure and cause psychological and behavioural alterations: fatigue, mood swings, and forgetfulness, amongst others (Wheelwright 2001). Thus, the suggestion is that Pyridostigmine Bromide (PB), the active component of NAPS, particularly in combination with other chemicals, may have done something similar to troops over a longer period. This line of reasoning implies that psychological aspects of GWS might have a neurotoxic explanation. This relates to the belief that their psychological symptoms and diagnoses of post-traumatic stress disorder (PTSD) are likely to be chemically induced (1). Veterans also use NAPS tablets to make sense of what they see as neurological symptoms, like pins and needles and clumsiness. This is further combined with theories involving OPs, which will be discussed below. We can see here how veterans' theories are complex, overlapping with other aspects of their system of thought in order to make sense of a whole range of issues.

Veterans develop theories using their past experiences. Central to this is the fact that NAPS tablets had given them a number of unwelcome side-effects during the war, such as: diarrhoea, stomach upset, constant need to urinate, constant erections/inability to get an erection. Rumours about NAPS tablets circulated during the war and many veterans reported feeling anxious about them. Indeed, a number

of my informants stated that they stopped taking them because of the adverse side-effects. Another contentious issue surrounding the vaccines and NAPS concerned their unequal distribution. Veterans and their advocates suggest that officers and aircrew did not accept all the preventative measures that the lower ranks were forced to take. Many aircrews indeed did not take NAPS tablets because one of their side-effects was frequent urination, which would have made long air trips untenable. This unequal distribution helps to explain, at times, why some were ill and others were not. Furthermore, it explains why so few officers were ill with GWS. Studies have shown that those from lower ranks are more likely to suffer from GWS (Ismail et al. 2000). This aspect of the system of thought is therefore able to respond to this finding. NAPS tablets and the vaccinations were not needed in the end since nerve agents were not used by Saddam Hussein, a fact which may have added to the subsequent anxiety surrounding them. There is a sense that they were an unnecessary, unused substance remaining in the body.

Discussions about NAPS tablets often overlap with concerns about organophosphates (chemical weapons, pesticides and insect repellents) because these compounds work in similar ways on the nervous system. A number of insecticides were used during the Gulf War and were focused on early in investigations into GWS. Mark and Debbie suggest that OPs are not a real concern for them and do not play a role in their theory of causation (18). This reveals the very individual nature and flexibility of GWS systems of belief, which are based on personal ideas of risk exposure. Having a different theory of causation from others is acceptable within the system, as long as your theory points to one or more of the exposures. It is a complex system, with people able to pick and choose aspects which are particularly relevant to them. Although Mark disregards the relevance of this exposure himself, OPs remain an important factor to others. No single thing affects all sufferers; in this way it is a closed system, as it cannot be contradicted. Ann, an ill veteran, emphasises the role of OPs amongst other factors in her narrative:

The other thing, I looked after a lot of evacuees and a lot of our lads as well who, the evacuees literally were covered in, they had been de-loused so they were covered in organophosphates powder and God knows what else. The lads came in from the front, their clothes were covered with what could have been sand, but we don't know what else so we bagged their clothing ... I think, again that the vaccines have caused this, or even the organophosphates ... And I think umm, that there may be something, maybe and again it hasn't been proven, but this squalene thing sounds like there was something that may have been added to boost our immune

system ... Because I think when I look at civilians, there is a lot of CFS, there is a lot of fibromyalgia. It's not just us that's got this. And for some of them, just for example, the organo-poison phosphate [*sic*], the organophosphate poison farmers, the sheep dip. That's a big thing at the moment.

At a later stage of the same interview Ann mentions two scientists to support the theory that organophosphates were involved in GWS. She points to the fact that one of these papers was published in the *Lancet* as further proof of its claims to expertise; veterans often refer to specific papers and particular scientists. Ann's narrative reveals the chaotic nature of theories of causation: there are just so many factors, so much information and so much at stake. She also shows the way in which these systems of thought constantly accommodate outside information and link it to a grand narrative. Thus, she connects the high incidence of CFS and the sheep dip-farmers movement, amongst other things, with her illness and GWS.

The concern surrounding exposure to OPs was introduced prior to the Gulf War; veterans subsequently encapsulated relevant themes into their understanding of the cause of their illness. In the UK "sheep dip farmers" had received a great deal of media coverage and the peril of OPs was well known to the public. Indeed, a number of advocates for GWS became involved through their dealings with OPs. The problems reported in farmers were the result of OP poisoning occurring after accidentally high levels of exposure to OP pesticides, either inhaling the vapour or spilling liquid on their skins. However, in the Gulf War there have been no reported cases of acute organophosphate poisoning. Instead, some researchers believe that a milder form of OP neuropathy affected the veterans, an exposure not characterised by any acute symptoms at the time. Alternatively, if there were symptoms, they were interpreted as flu, effects of vaccines or stress of war. The belief is that organophosphates are not only toxic in themselves (Jamal et al. 1996; Haley et al. 1997a; Jamal 1998), but interact synergistically with other pesticides, multiplying the overall toxicity of these compounds (Abou-Donia et al. 1996, 2000; Abu-Qare et al. 2001).

Veterans often speak about Robert Haley, the leading proponent of neurotoxic injury and one of the most heralded and respected scientists within GWS circles, who advocated this theory and focused on the issue of delay in OP poisoning. His theory is that low levels of these chemicals injured the soldiers' brains. Chemical weapons are a causal feature in Haley's theory of GWS, which he links to the nerve gas that was released when the US bombed Iraqi weapons plants on the fourth

day of the Gulf War.<sup>9</sup> Haley put 23 sick veterans and 20 healthy ones through detailed scans and said he had detected damage to their deep brain structure. Haley stated that GWS was due to brain damage from sarin. Furthermore, he introduced a genetic element to his theory, suggesting that some did not become ill while others did because they lacked a common enzyme that protects the body from toxic chemicals such as nerve gas and PB.

In January 1997 the *Journal of the American Medical Association (JAMA)* published three of his papers in the same issue, immediately placing Haley at the centre of the Gulf War debate. Although welcomed enthusiastically by veterans and their advocates, Haley is highly criticised by the mainstream scientific community involved in GWS research. He was charged with recall bias and selection bias as he had confined his sample to a suggestible, high-profile reserve battalion called 24th Navy Seabees. Haley used a small number and had not used a control group, a fact which greatly diminished his findings, according to his critics. It was also suggested that the neurological differences between the sick and the healthy study participants was due to other factors such as chemicals at their civilian jobs, or personal habits such as drinking, anxiety or depression (Wheelwright 2001).

Another GWS scientist who focused on OPs as the cause of GWS was Mohammed Abou-Donia. He suggested that DEET, PB and permethrin were more toxic to animals when administered together than when given singly. Critics point out that both Abou-Donia and Haley were funded by Ross Perot, the suggestion being that this may have meant they were biased. Perot, the Texan millionaire politician, had become interested in the veterans' cause when he was running for President of the United States.<sup>10</sup> It has been suggested that it was in his interest to be seen to support veterans in their battle for recognition of the illness and, thus, those researchers he supported financially would do so too. However, this argument echoes the veterans' and their supporters' belief that any work paid for by the US Department of Defence or MoD

9. The US Pentagon reports deny Haley's assertion. They say that no Iraqi chemical weapons were bombed on the fourth day of the war and that any bombing on that day was more than 200 miles away from the group Haley studied.
10. Throughout the book I use material from both UK and non-UK sources. Although it is wrong to assume direct comparisons, I believe these sources can shed light on the issues raised. Importantly, GWS appears to be quite similar in the countries where it has appeared (Canada, US, UK, Australia) and it is from these countries that I use additional material. Furthermore, militaries can be seen as sharing cultural characteristics and these particular militaries are often in contact and share experiences. Veterans themselves move fluidly between UK and other sources, while GWS itself is a product of a dialogue between these various arenas.

is biased in the opposite direction: disputing the existence of GWS as a unique disease category.

One exposure which is missing from Mark's account is chemical weapons. Although he and his wife do not mention it, exposure to chemical weapons is often included in veterans' theories of causation. At the AGM Malcolm Hooper, the veteran's scientific advisor, went into detail about the various exposures and causal theories. He spoke at great length about Haley and his work, saying that Haley had found a genetic link in that some people were more susceptible to things like sarin:

Oops, we weren't exposed to sarin gas, says the MoD. The Americans have now admitted that they were. We are still playing silly buggers at this, sorry about the language, but I just get so cross. I'm preaching tomorrow as well so I'd better be careful [everyone laughs]. But these are the sort of things that we are seeing. "Oh, there's no evidence that we were exposed to sarin gas". What about all the alarms that went off? "Oh, they didn't work". Why did you buy them then? Why did you claim there was no exposure if the alarms went off anyway?

Concerns about chemical weapons are more often expressed through reporting of the frequency of the NAIADs (the alarms used to detect chemical weapons) sounding. Chemical weapons alarms went off frequently during combat and were regularly ignored, something that many veterans use to support their theory. However, it was later suggested that the alarms were too sensitive and reacted to things like jet fuel. It was reported that nerve gas was noticed by Czech military teams on 19 January 1991: two days after the beginning of the war on the ground. Five days later, the same teams detected mustard gas (*The Economist* 1997).

Many veterans referred to the 'Khamisayah incident'<sup>11</sup> and in some cases showed me a map which detailed the "plume" along with where they had been located in relation to it. Importantly, John's 205/32 Field Hospital was said to have been located in an area which was near the plume; thus, the link between the illness, that particular field hospital and the veterans' association was strengthened. However, the plume diagram kept changing and veterans complained if the updated plume

11. The Khamisayah incident refers to 4 March and 10 March 1991 when the Khamisayah ammunition depot was detonated, probably releasing sarin into the air. Deadly levels were not attained and no gagging or gasping by the US troops on the scene was reported. When details about the incident were first reported 400 veterans were said to be at risk. Later, the number was raised to 1,100, 5,000 and then 21,000. The fact that it took so long for the American government to disclose the event added to accusations of cover-up.

left them out of the area. The Khamisayah incident added much fuel to the GWS fire, particularly to accusations of cover-up. The incident was first reported on the front page of the *New York Times* and other newspapers on 22 June 1996, five years after the war (Wheelwright 2001). The reports referred to the fact that the Pentagon had disclosed that troops may have been exposed to nerve gas shortly after the war when an army unit blew up an Iraqi ammunition depot that contained rockets armed with chemical agents. The revelation was immediately linked with a possible explanation for GWS. However, this theory is not absolute, as it did not explain why those who were not near the incident are reporting similar symptoms.

Despite focusing on his location in the Khamisayah plume, his exposure to chemical weapons and endorsing Haley's theory, at one stage John completely dismissed the role of chemical weapons. He told me that initially he had suspected chemical weapons, but now dismisses that theory in favour of issues like DU. The shift in theory, he suggests, was due, in part, to the increased focus on DU in the media due to Bosnia and Kosovo, but also because he had come to accept that had chemical weapons been released people would have died at the time. This dismissal of chemical weapons contradicts Haley's theory, outlined above. We can see the way in which veterans use different, often contradictory theories at different times. They use part of Haley's theory to develop their own, ignoring other parts which do not fit into their model. It must also be noted that when veterans were advocating Haley's work they did so seemingly without awareness that by doing so they were contradicting other theories, since Haley's theory suggests that DU, vaccines and oil fires are not factors in GWS. Although veterans and Hooper often refer to Haley, they mainly focus on his "proof" of brain damage and links with psychological symptoms.

Depleted uranium is mentioned by both Mark and Debbie as a likely cause of Mark's illness as well as the children's problems (9, 21). Indeed, Debbie reports that one of her doctors made the connection between the health problems of their children, the problems found in Iraqi children and DU. DU is most commonly cited as the cause of birth defects and reproductive problems of veterans and their partners (see Chapter 7). It was used as "tank busting" ammunition by US and UK troops. Thus, it would seem that only victims of the friendly fire incidents between the US and UK<sup>12</sup> were at risk from direct DU

12. During Gulf War An American A-10 attacked British armoured personnel carriers, the incident resulted in the deaths of nine British soldiers and the serious injury of another twelve British soldiers. In addition, 35 of the 148 American servicemen and women who died in the Gulf War were killed inadvertently by their comrades.



exposure. However, many veterans believe that they were exposed to depleted uranium in a more indirect manner. Veterans suggest that they had "breathed in or ingested" DU dust as a result of coming into contact with or handling either Iraqi or friendly fire victims. The other suggestion is that there had been a large, unknown amount of DU in the general atmosphere as a result of the ammunition. Often, contact with DU involves discussions of the enemy and the Basra Road incident.<sup>13</sup> As Jack describes:

I mean, I was on an armoured reconnaissance regiment and we had some DU shells which we weren't warned about. Once the war had finished we were on the Basra high road and some of our lot was responsible for burying bodies, etc; and again, without being ghoulish, once any conflict like that has happened, one thing you do is you look over war trophies. Now, we were ... because it was the first chance to look up close at various military tanks, armoured cars, armoured personnel carriers, etc; we were clambering all over these vehicles: one to look at the vehicles and two to bring back ... whether it be a helmet or whatever. And we were clambering all over these vehicles that had been hit by DU but we didn't have a clue.

Souvenir hunting and being on the Basra Road implies contamination by DU. Mark's opinion was that those who were ill as a result of coming into contact with DU while souvenir hunting "deserved it". Some veterans combine discussion of psychiatric problems (PTSD) with a discussion of depleted uranium. The trauma of handling dead bodies is entwined with the DU on the same bodies.

The various causal theories are outlined on the GWVA's website. On one webpage Hooper goes into great detail in explaining the role of DU in the illness:

Undoubtedly DU exposure has contributed very significantly to the illnesses now suffered by some GWVs,<sup>14</sup> their families, and the civilian population of Iraq including the unborn ... There is a 250,000-fold excess of babies born without eyes in a study from Baghdad, De Sutter, 2001. Research commissioned by the GWVs themselves has shown that some of them are still excreting DU some 8–10 years after the Gulf War, Durakovic<sup>15</sup> et al.,

13. At the end of the war American planes had attacked a mass exodus of Iraqis trying to escape in any vehicle they could, including tanks, ambulances and ordinary cars. The result was a mass of dead and burnt bodies and burnt-out vehicles (de la Billière 1992).
14. Gulf War Veterans.
15. Durakovic is a scientist involved in GWS who studied UK Gulf veterans; he reports finding that some of the sick were excreting DU in their urine. He further suggests that this could be causing GWS (see Durakovic 1999, 2001).

2002. This clearly indicates slow elimination of DU from internal body stores that were laid down in 1990–1. The cumulative internal radiological dose from that date is thousands of times the allowed dose advised by the national and international agencies, Busby, 2000 ... Environmental damage is also extensive with grossly deformed plants and animals being reported ... Cancers expected as a major consequence of internal exposure to DU are lymphomas, leukaemia, lung and kidney cancers.

The above discussion by Hooper is extremely important because veterans look to him as the supreme expert in GWS issues, as will be discussed below. DU is linked by Hooper to cancers and birth defects and he explains that DU remains in veterans' bodies and is slowly being excreted out, something which is testable. Ann reports:

It's a scientific fact that I've been exposed to depleted uranium. I was tested in 1998 by Durakovic and this was showing levels that were over 100 times the safe limit of what I should have been exposed to over the period of a year. And this was several years after I had been exposed. I've had chromosome aberration test done in Germany. And low-level radiation expert saw a result that showed three times the biological damage as the residents of Chernobyl showed at the time of the disaster. That's a scientific fact.

Ann mentions the name of a scientist who was very much involved in the GWS movement and who focused on DU as the cause of the illness. Chernobyl is often referred to in discussions about DU, as veterans absorb other theories. The link between radiation, Chernobyl and DU is further developed into belief systems about GWS and problems with offspring. Above, Hooper suggests that DU is radioactive and will remain in Iraqi land, continuing to harm civilians and the environment. As John notes,

What I know about DU, the considerable lack of knowledge with regards to chemicals exposure we had and that and what side-effects could be cause ... it's a carcinogen ... depleted uranium is a heavy metal toxin and its chemical compound, and it's very worrying ... DU has a chemical half life, a biological half life of, 500 million years, so it has nowhere to go. And I think that's an issue.

In his long list of causal features of his illness, Mark presents smoke from oil well fires as something he was exposed to and a contributory hazard (10). Oil well fires were regarded as the first culprit of GWS, but soon lost favour as anything but a subsidiary danger. Most of the veterans I interviewed listed a number of exposures – oil fires among them – yet exposure to oil fires remains a minor feature. Many

veterans would, however, describe their experience of the fires by saying, "the sky was black", "day turned to night" – thereby emphasising their experience of exposure.

One theme that emerges repeatedly in the above narrative is the assertion that the *combination* of the exposures is a likely culprit in the illness (5, 12, 14, 23, 24). Although each substance is seen as new and therefore dangerous, the uniqueness of the unknown combinations of these substances is also a cause for concern. As mentioned above, many of the theories involve the notion of synergism. Most veterans stress the role of the "cocktail effect" of the various exposures. Hooper constantly refers to the Gulf War environment as totally novel – "the most toxic war" – and describes the atmosphere of the Gulf as "a witch's brew of toxins". The image is of a toxic soup, with a number of dangerous and unknown substances mixing together, creating new and even more dangerous materials. Importantly, it is suggested that all the possible combinations could never be fully researched, leaving the cause of GWS out of reach. Since there were so many possible combinations, with the added possibility that different combinations affected different people, the cause remained elusive. The sheer number of possible combinations of exposures and their different and unique effects on individuals means GWS theories of causation are fairly impenetrable.

When listing all the possible factors which may have caused his illness, Mark mentions the adrenaline in his body (11). Many veterans add other non-exposure factors which may have contributed to their illness, possibly in combination with the other exposures. Veterans mention the heat, the NBC suits,<sup>16</sup> dehydration, lack of water, lack of alcohol, and unknown entities like viruses and diseases as potential contributory factors, adding to the already abundant and complicated theories.

When discussing the long list of possible explanations for his illness, Mark mentions the fact that he was given unlicensed drugs (7). This is a theme which dominates most veterans' accounts of the cause of their illness. Veterans emphasise the newness of the substances and that some of the exposures were untested, unlicensed, secret and experimental. They link this to the way in which medical and other

16. Nuclear, Biological and Chemical Suit. The full-body suits which were to protect against possible nuclear, biological or chemical attacks. The suits were donned often due to the perceived threat. Also called a "Noddy suit". Veterans often had to don them quickly, when the NAIAD alarms sounded. They were described as hot, cumbersome and claustrophobic.

relevant records were not kept or lost, and to grander conspiracy theories, as the following discussion with John and Jack reveals:

*John:* The deliberate loss of medical documentation, the destroying of medical documentation ...

*Jack:* Other wars have [lots of paperwork], so obviously the MoD and the government know that things happened in the Gulf that shouldn't have happened. Either there were exposures that we shouldn't have been exposed to or we were given stuff that we shouldn't have been given. And so they went out systematically, methodically destroying documentation ... The doctors can't treat you because they aren't aware of what you've been given. And, in fact, because they are withholding information from doctors, doctors could, technically, prescribe us with something that makes us even worse.

*John:* Vaccines were not licensed to be used in the UK because of the contradictory effects ... according to all the rules and regulations at the time, it was an erroneous prophylactic programme that they gave us. And they shouldn't have done it. They were advised by the Department of Health not to give us those vaccines in that manner ... should not have given perutussis [*sic*] in conjunction with the anthrax vaccine ... The recommendation on that clearly states, 'not for adult use'. The vaccines and medication were experimental. Never been used before ... It was the first time that the vaccines were given, vaccines that were classified secret were given, anthrax and perutussis [*sic*], the first time they were given, in conjunction. The first time that NAPS tablets were given ... Depleted uranium: the first time that had been used in a war. The first time the British army and the United States had used it in a battle environment.

*Jack:* Again, it was experimental in the Gulf. Like a lot of things, like the injections, like the NAPS, like so many other things [...] The first time people had come into contact with oil well fires. Possible other contamination with Iraqi chemical works being destroyed. First time that people have come into contact with those sorts of materials [...] DU was experimental in the Gulf ... um but again it's an experiment. What better way then try out all your experiments, your new injections, your new toys, your new weaponry, what better way to have a real live war? Great, it's not on our doorstep we're not going to be affected anyway. If we go in and if we affect the country so what?

The notion of the war as a large-scale experiment relates to the title of this chapter; veterans see themselves as guinea pigs, lab rats upon which the government could do as they pleased. Concerns about the untested/unlicensed nature of the preventative measures developed from information veterans received. NAPS, for example, was not licensed for specific use in warfare at the time the Gulf War, although they are now.

However, PB has been successfully used since 1955 to treat men and women suffering from the neuromuscular disease *myasthenia gravis*. The belief in a conspiratorial experiment is further strengthened by many veterans' assertion that officers, pilots and the Special Forces did not take the same medication as other soldiers. Thus, issues of class and rank are tied up in discussions of the illness and help veterans to make sense of the statistics which report that officers are unlikely to suffer from GWS.

John claimed that some units were clearly being monitored as part of an experiment:

At the end of the war there was a RAF medical unit going around from unit to unit and asking about NAPS tablets and effects, side-effects. Also, some of the units were bled ... Blood was taking off them after the war, while they were still there. And some of the units were bled before they went out. So, particularly 205, for instance, the general hospital: that was bled before it went out. Bled after the ground war, before they all came back. To see what the uptake was on the vaccines and at the end of it, which is an experiment. There is no two ways about that. That is an experiment.

The issues of novelty and secrecy often involve specific examples in veterans' accounts. The interviews from which I have taken these narratives were conducted early in my fieldwork. Theories are constantly changing and adapting, though. Whereas John briefly mentioned a substance called "squalene" as a possible factor, Mark and Debbie did not mention it at all. Squalene was to take a major role in theories of causation a few months later. Concerns about the role of vaccinations in the illness took a new trajectory as veterans became aware of a substance called squalene.<sup>17</sup> During the association's AGM in March 2002 much of the formal and informal discussions focused on squalene. A persistent allegation about the vaccination programme is that this substance was added as an adjuvant<sup>18</sup> to the vaccines. The US and UK governments have denied the use of squalene in the vaccinations. However, in 2000 a Tulane University researcher, Pam Asa, claimed to have found antibodies to squalene in veterans' blood. The reason for this interest in squalene was largely due to a recent media story and the presence of its subject at the AGM. Gwen, a non-

17. A naturally occurring substance, squalene is produced by the liver to help metabolise cholesterol. It is found in shark liver oil, some vegetable oils, cosmetics and various nutritional supplements. It is also used as an adjuvant in some vaccines.

18. A substance used in a vaccine to improve the immune response so that less vaccine is needed.

deployed ill veteran,<sup>19</sup> had been the subject of a television broadcast about GWS and vaccinations. The programme took Gwen to meet with Asa in the US and filmed her as she tested positive for squalene antibodies. After the programme was aired the GWVA contacted Gwen and she became a member of the association.

During the AGM an information sheet on squalene was made available. It said:

What makes Gwen unusual apart from her diagnosed Gulf War Syndrome is that she never actually deployed to the Gulf ... Thereby proving beyond a reasonable doubt that the vaccines made so many of us ill and not chemical weapons or environmental factors. Particularly not the stress of battle!

The information sheet also quoted Asa as saying that her findings ruled out the alternative theories of causation for GWS, something which was not taken up further by veterans as they continued simultaneously to subscribe to theories which involved other exposures. During the AGM one of the main interests was the taking of blood from participating veterans in order to test for squalene antibodies.

Genetic factors are also introduced as a causal agent in Mark's narrative (13); he refers to a specific paper which suggests this. As mentioned above, genetics are seen to contribute to GWS, outlined in Haley's theory. Given the central role of genetics in understandings of disease in Western culture, it is not surprising that veterans embed their understanding of their condition in genetic theories. Ann presented a long, jumbled list of causes of her illness, amongst other factors suggesting a possible genetic contribution, but introduced a different scientist to support her claim.

The MacNess team ... found was that all the Gulf veterans, regardless of how many symptoms they had had a 50 per cent reduction in this paronoxinase. Which detoxifies organophosphates. And what is it? It's an enzyme. And we have genetic differences in them. So that in some ways explains why some people got sick and some people didn't get sick.

In her discussion, Ann suggests a genetic pre-disposition or vulnerability to organophosphates and refers to a scientific paper

19. Gwen is one of a significant group of soldiers who were not sent by the military to the Gulf War, but have GWS. The suggestion is that some, like Gwen, were vaccinated in preparation for war, but in the end were not deployed. Others claim that they became ill after working on machinery, such as tanks and trucks, which had been in service in the Gulf War and were potentially contaminated with exposures, such as DU.

written by one of the "sympathetic" researchers to support her argument. This one part of her overall theory provides a grand narrative which makes sense of and links a number of factors. In so doing she points to scientific studies and experts, rooting her language in the medical world.

As demonstrated above, veterans encompass other theories and beliefs from the world around them into their system of knowledge, such as including a genetic reading of the condition. Mark and his wife also discuss food allergies and autism as being linked to GWS (16), as well as the MMR debate (20). Importantly, MMR, food allergies and autism have all received a huge amount of media and public attention over the past few years, making them accessible theories with which to work. Thus, many veterans and their children have been put on special diets, such as dairy-free and gluten-free diets. The reason for this is that advisors such as Hooper and his colleague Paul Shattock have suggested a link between vaccinations, gut permeability, autism and sensitivity to certain foods.

## **Risk**

Veterans view the world as full of risk. GWS narratives are saturated with discussions of dangers in the form of chemicals, toxins and viruses. These risks are central to their theories of causation: Gulf War exposures rendered them ill and leave them vulnerable to other hazards. Like many of us, they are far more likely to view symptoms as pathological and interpret them in a medical rather than a social or normative context. The popular belief is that the physical world is a potentially hostile place, full of chemicals, toxins and viruses that are eroding health and well-being. GWS should be seen against the background of a larger cultural trend which has witnessed increasing anxiety about health and a heightened link between identity and the body. Although objective indices of health have improved during this century, surveys suggest that modern man feels less well and experiences more symptoms than in previous generations – something which has become known as the paradox of health (Barsky 1988; Barsky and Borus 1995).

Modernity is a risk culture (Giddens 1991: 3). The concept of risk has become fundamental to the way both lay actors and technical specialists organise the world (*ibid.*). In the contemporary Euro-American context, risk is impossible to ignore and is central to understanding health beliefs and behaviours. Three social scientists have written extensively on risk: the sociologists Ulrich Beck and

Anthony Giddens and the anthropologist Mary Douglas. Both Beck and Giddens see the world as entering a new phase, which they respectively label “reflexive modernisation” and “late” or “high modernity”. Risk is central to this transformation, with new perils being introduced that other generations have not had to face consciously.

Beck and Giddens emphasise the trend towards individualisation in late modernity, but Douglas’ work focuses more on the social nature of decision-making in respect to risk. In line with Douglas, an investigation into GWS reveals that the process by which people assess dangers is very much a social process, negotiated between individuals and institutions.<sup>20</sup> Furthermore, it is constantly re-assessed and re-negotiated as veterans are confronted with new information and experiences.

As her work on the subject is a continuation of her work on purity and pollution, Douglas (1966) also introduces *morality* in understanding risk and danger. She argues that distinguishing something as a risk is a way of making sense of the world as well as a method of keeping things in their proper place. Risk in our culture plays an equivalent role, Douglas states, to taboo or sin, but it acts in the opposite way: it protects the individual against the community.

Being “at risk” in modern parlance is not the equivalent but the reciprocal of being “in sin” or “under taboo”. To be “at risk” is equivalent to being sinned against, being vulnerable to the events caused by others, whereas being “in sin” means being the cause of harm. The sin/taboo rhetoric is more often used to uphold the community, vulnerable to the misbehaviour of the individual, while the risk rhetoric upholds the individual, vulnerable to the misbehaviour of the community. (Douglas 1992: 28)

Those that put others at risk are acting immorally. This feature of risk assessment is linked to the way in which blame is designated and explanations found for misfortune and illness. The blaming system:

[W]e are in now is almost ready to treat every death as chargeable to someone’s account, every accident as caused by someone’s criminal negligence, every sickness a threatened prosecution. Whose fault? is the first question. Then, what action? Which means, what damages? what

20. Beck and Giddens emphasise the trend towards individualisation in late modernity, but Douglas’ work focuses more on the social nature of decision-making in respect to risk. In this way, as Caplan (2000) points out, the way people deal with risk appears closer to Douglas than to Beck and Giddens.



compensation? what restitution? and the preventative action is to improve the coding of risk in the domain which has turned out to be inadequately covered. Under the banner of risk reduction, a new blaming system has replaced the former combination of moralistic condemning the victim and opportunistic condemning the victim's incompetence. (Douglas 1992: 15–16)

Linked to this new focus on risk is our inability to accept chance. As we see in veterans' narratives, every illness or misfortune must have a cause and someone must be held accountable. Institutions and large corporations are generally seen to be immoral and risky in that their practices put others at risk, and it is towards them that we point the finger of blame. The MoD put veterans in danger by injecting them with and exposing them to harm, even by the very nature of sending them to war. Mobile phone companies, the government, drug companies: all are responsible for putting us in peril and making us ill. Someone is responsible. It is in this way that people develop chains of causality.

We have witnessed a change in the meaning of risk; the concept now only denotes bad risk (Douglas 1992). Those institutions and apparatus that were once seen as benign, or even beneficial, are now seen as potentially harmful. Risk is invoked as a response to the abuse of power. "For those purposes *danger* would once have been the right word, but plain *danger* does not have the aura of science or afford the pretension of a possible precise calculation" (Douglas 1992: 24). Perceptions of risk are often linked with past experiences and theories of causation. Science is increasingly replacing mechanistic models of the body and illness by new interrelated discourses of environment, immunology and genetics and as a result there is increasing frustration with scientific explanation (Cohn 2000). Because of the multi-layered nature of these new discourses, people experience the diffusion of cause and the accompanying loss of moral resource (Cohn 2000). Cause (and blame) is no longer straightforward.<sup>21</sup>

The new concern with risk is partly a backlash against the great corporations (Coleman 1982 in Douglas 1992). Indeed, it would seem that faceless, large institutions, like the MoD are seen as inherently dangerous and risky. The "political pressure is not explicitly against

21. Critics of Douglas and Wildavsky have pointed out that they reduce real risks to metaphor and, by so doing, eliminate danger all together (Kaprow 1985 in Caplan 2000). Hacking (1982: 31) claims, "*Risk and Culture* sometimes hovers near the anthropological fallacy of thinking that everything we perceive is a cultural artefact. Every once in a while the reader has to cry out that some pollution is real."

taking risks, but against exposing others to risk” (Douglas 1992: 15) The anthropologist Ernest Gellner has convincingly argued that our movement into a global society is at the heart of risk being central to modern life (Gellner 1984). Modernity is characterised, he says, by new social relations as we move from the local community to larger national and international spheres. This is reminiscent of Weber’s description of the “iron cage” of bureaucracy (Weber 1930: 181). Douglas suggests that “liberation from the small community also means losing the old protections. The markets suck us (willingly) out of our cosy, dull, local niches and turn us into unencumbered actors, mobile in a world system, but setting us free they leave us exposed. We feel vulnerable” (Douglas 1992: 15). The focus of this vulnerability becomes invisible and ever-present dangers, such as toxins and chemicals. Thus, our late twentieth-century/early twenty-first century malaise is blamed on viruses and toxins, with the ultimate bearer of responsibility wresting on large institutions.

## Conclusions

The veterans’ theory of the cause of their illness is not unitary and consists of a large number of possible explanations. Although there seems to be a finite number of advanced exposures, the different combinations provide a vast array of possibilities. Furthermore, individual differences, both in terms of exposure experience and bodily composition, add to the inclusive theories. It is necessary to see GWS and the veterans’ concerns in context. The veteran’s view that the world is full of risks is not unique to their plight. Over the past decades there has been the increasing perception that risk is ever-present and is in the form of invisible viruses and toxins. In the Euro-American context in which GWS emerged there has been an increased focus on risk, with a specific emphasis on the way in which toxins and chemicals impact health. An important characteristic of risk assessment is the way it allows for blame to be assigned. When veterans try to make sense of what caused their illness they present a series of possibilities, sometimes with conviction and sometimes with uncertainty; but the one thing they are certain of is that the Gulf War made them ill.

## Chapter 2

# **CHAINS OF CAUSATION, CHAINS OF KNOWLEDGE**

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### **Introduction**

This chapter continues to explore the themes contained in GWS explanatory model(s) and meaning systems. I will be referring and adding to Mark and Debbie's extended narrative in the previous chapter and supplementing it with data from other veterans' accounts. The issue of cause is central to GWS theories, but there are levels and chains of causality, which provide a great deal of flexibility. Contained in these narratives is a search to make sense of a variety of experiences: a search for meaning. Questions about information, knowledge, truth and expertise are woven into veterans' narratives and are impossible to separate out from the issue as a whole.

### **Contested Knowledge**

Giddens (1991) and Beck (1992) argue that a fundamental characteristic of modernity is that faith in science and scientists has been eroded. Knowledge is contested. In reflexive modernity people are no longer content to accept the truth claims of scientific knowledge. Instead, they subject them to scrutiny and criticism. Furthermore, science itself is divided in terms of what constitutes a risk, making the public more uncertain. There "is substantial, sometimes radical, disagreement within

the medical profession about risk factors as well as about the aetiology of major health hazards” (Giddens 1991: 121). These issues are central to understanding GWS and its system of belief. People do not trust experts because they themselves generate anxiety (Beck 1992). Late modernity is characterised by a critique of the concept of modernity whereby central institutions (science, industry, government) “are seen as no longer unproblematic (producing goods) but instead as producing many of the ‘bads’ from which we feel threatened” (Lupton 1999: 3). Whereas the central institutions used to be seen as entirely positive in that they produced objects and knowledge that benefit humankind, they are now seen as the main producers of risk.

An emphasis on risk, Beck and Giddens assert, is thus an integral feature of a society which has come to reflect upon itself, to critique itself. Risks produced under late modernity have increased in magnitude and become globalised, thus making them more difficult to manage and avoid (Lupton 1999).

There is such an abundance of information that it is impossible to absorb it all, and yet one is able to pick and choose – utilising that which fits into the model we construct. Douglas has shown the way in which misreading “evidence was an important theme in the history of science, where the same evidence was sometimes used to support alternative theories” (1992: 8). Fortun suggests that in the social context of GWS there is a huge amount of information, “yet also abundant suspicions that available information is incomplete or even fraudulent. It is about extraordinary desire for understanding, coupled with keen awareness that the complexity of the issues defies the possibility of expert comprehension” (1999: 344).

During my interview with Mark and Debbie, they discussed systems of knowledge and expertise. In this section I focus on the construction of knowledge of GWS and the creation of knowledge networks. The following excerpt continues on from where the interview with Mark and Debbie left off in the previous chapter. Mark explained:

[25] It seems to be the older people who seem to be suffering that bit more ... I think the problem is that we are not at the same stage. It seems to affect different people different ways. If you see the veterans [at the AGM] and that you see that a lot of them, and again, it’s not people who knew each other in the Gulf or knew each other before they went to the Gulf.<sup>1</sup>

1. See Chapter 5 for a discussion of veterans’ dismissal of studies that suggests that the strongest association found with GWS sufferers is knowing another person with the illness.

On the whole I think GPs are frightened to put their head up and say this could be a Gulf War issue. [26] Um, [my GP] relies on us for a lot of things and we rely on word of mouth of other people who might have seen a doctor who was sympathetic, or who was quite good. [27] [We mainly rely on] other veterans, basically. [28] The neurologist in Glasgow whose is backed by the GWVA and they are in touch with Dr Jamal in London. He was at Glasgow. He had quite an interest in it. But for some unknown reason he got his funding withdrawn in Glasgow and that's how he ended up in London. But he knew Dr Cleaver who is the other one ... but he is the one who, he is a specialist in Chronic Fatigue, but he sees a lot of similarities between the Chronic Fatigue and the Gulf War patients. So he said he would treat us as Chronic Fatigue rather than Gulf War. He would see us as Chronic Fatigue patients because he was, if he was to say Gulf War the same would happen to him as would happen to Dr Jamal. As soon as Dr Jamal mentioned the Gulf War his funding was started to withdraw from the stuff that he was doing.

[29] Whether it's Chronic Fatigue or the Gulf War. The fact is that the only thing that a lot of us have in common is the Gulf. So even if the Gulf is causing Chronic Fatigue it's still something that they have done that they are not prepared to accept that they've done. But again that's only one part of the illness that they've found something. That's only the fatigue part and the headaches, but that's nothing to explain the joint pain and the headaches. Um and the memory loss kind of thing. It's like taking it bit by bit. You've got to take it the overall picture of it all.

[30] [Where do you get information from?] Mostly there are emails from America. Or they will send you a site to go to on the Internet. More information comes from America then anywhere else. If you look at the money they are spending.... [31] I don't think they [the UK studies] are working with all the information. Um, the latest one that came out from Professor Spratt. Not so long ago and then it turned out he didn't have all the information to make a true assessment in the Gulf war issues [...] He was mainly about the DU things and that. But even before he did his study he was on the radio saying that he was sure that DU was no problem. And that was right before his study had even started. I don't see how he could say that and be objective in the study he was doing. I think the problem is that most of the studies that have taken place have been funded by the MoD ... so they are not what you would call impartial. And those studies, I think that's the main problem that we've got in the UK. Most of the people that have been independent studies have found different conclusions to what the MoD have come up with ... backing what people believe, but the same could be said for the MoD, they are backing the ones that they believe and try to rubbish anything that comes out on our behalf and we are the same, anything that comes up backing them up we are quite quick to rubbish that as well. I think that what we need is an independent body set up and try and look at it with input from the MoD and from us, but nobody holding an influence over it. Totally independent from both of us. Because at the moment if the MoD hold a study we obviously see it as biased towards the

MoD and if we have something that comes out they see it as biased towards us and I think you are always going to get that, until there is something that comes out that is totally, totally independent.

Contained in Mark and Debbie's narrative is an account of networks of knowledge and information. Such systems are central to understanding GWS theories. To whom do veterans listen? Who do they consider experts? Who and what do they dismiss? Central to this discussion is a question of professional expertise versus lay expertise, and work which has been done on the public understanding of science. McKechnie points out that Latour (1986) urges social scientists to follow science out into the world, but she suggests the importance of following science from the world, and tracing its path partway back. The "assumption is that science, and its practitioners, are not the only, and perhaps not the principal, actors involved in the social construction of scientific authority. It is not a one-way process. The whole of society participates in identifying 'science' and 'expertise', as it does in the identification of any important symbolic boundary" (McKechnie 1996: 130).

Mark suggests that his doctor does not know much about the illness and, thus, defers to Mark himself as the real expert (26). In fact, he suggests that the doctor is afraid; that medicine is tied to issues of politics. So veterans turn to each other for information about their illness (27). Most, if not all, sufferers report that they rely on other veterans and the association for scientific information. The Internet is central to this sharing of information as it connects veterans from all across the UK and, indeed, across the world. Experiential expertise rules in GWS circles, with the public and media seeing veterans as the only true experts of the illness. One of the leaders of the association was keen to emphasise the medical knowledge of many of the veterans, furthering their claim on expertise. I was often told that many were medically trained; thus, veterans still wish to ascribe to traditional notions of expertise and insist on a medical foundation for the debate.

In looking at the creation of knowledge networks, the very question of the separation between these experts and the public is thrown into question. Most anthropological studies champion "lay perspectives" and have revealed a great deal about the way that patients and other lay persons respond to new technologies and knowledge as they are applied and/or disseminated into a "wider world". Those exploring how "publics" respond to science in a broader sense have shown that this is constituted by action, rather than just a simple process of passive reception (Irwin and Wynne 1996). Martin's (1994) work, for example, illustrates how ideas about the immune system "travel" and change between different publics and sciences. A lay/professional distinction

has been used in a variety of domains relating to medical practice or the use of scientific knowledge in order to highlight the differing ways that those subject to forms of knowledge experience or make sense of them. This has been most usefully demonstrated in relation to risk information and figures (Beck 1992; Douglas 1992; Lupton 1995).

Mark mentions a few doctors by name and suggests that there is a group of doctors and scientists that other veterans have found who are “sympathetic”, suggesting that medicine is not pure or homogeneous and open to individual beliefs (28). Furthermore, he describes a kind of system in which these doctors or scientists are in touch with each other and direct veterans to follow the chain of trusted, sympathetic experts, creating a closed community. Many veterans have met the scientists whose theories they advocate; indeed, many have been studied by them. Scientists are often referred to personally and are evaluated on factors other than their scientific credibility. McKechnie (1996) found in her Isle of Man context that scientific knowledge played an unimportant role in the credibility of figures singled out as “experts”. Instead, integrity and competence in everyday life were central concerns; trust and authority were heavily contingent.

Within research into public responses to scientific issues there is a tendency to dismiss as irrelevant moral evaluations of persons and institutions (McKechnie 1996). In the GWS movement I found issues of trust and personal evaluations to be central to decisions about who was or was not considered an expert. Most importantly, experts were those who support the veterans’ rendering of their condition and who accept the expertise of the veterans themselves. It is now accepted that trust and credibility are major contextual factors influencing the uptake and understanding of scientific messages and the public perception of risks (Wynne 1980, 1992; Slovic 1992). Wynne (1996) shows how issues of trust are embedded in changing social relationships and constantly open to renegotiation. Veterans’ interpretation and acceptance of scientific findings are embedded in the context of their social relationships and are based on a complete mistrust of one side of the debate. Trust, however, “is a profoundly relational term, a function of the complex web of social relations and identities” (Wynne 1996: 40).

Mark suggests that there is better, more valuable, more truthful information coming out of America and continues to suggest that UK studies are flawed (31). Throughout my fieldwork I found veterans talking about other countries as the place where veterans were more believed and better treated. UK veterans suggest the US and Canada are more sympathetic, and vice versa. UK veterans, like Mark, believe UK studies to be flawed due to their MoD or government funding. Mark also admits, however, that veterans are guilty of only backing the

findings that comes out supporting their understanding of the illness. He suggests the need for a purely independent and impartial body. Irwin et al. suggest that the plea for totally “independent expertise” in practice is impossible but that it “seems to suggest that there is seen to be such a concept as ‘pure’ science”<sup>2</sup> (1996: 57). In their study of perceptions of local environmental threats, this notion was not within the everyday context as defined by residents, however. There was a sense that science was “out there” in the same way as veterans perceived pure science to be possible – with other countries having come closer to attaining it.

Mark also discusses the way in which those who are “sympathetic” to the GWS cause are the victims of conspiracy. In his narrative, Mark describes a divided world of good and bad scientists. The good scientists, like the neurologist and Dr Jamal, support and legitimise veterans’ theories, but by doing so are left vulnerable to unknown, evil forces of government and funding. On the other side are scientists like Dr Spratt, who are biased, not impartial and linked to the MoD. According to a number of veterans, the fact that Dr Spratt was recorded as saying he did not think DU was a problem before he had completed his study is evidence of his questionable scientific credibility. Throughout my fieldwork I found that any study that reported findings which were unacceptable to the veterans was easily dismissed by pointing out that it had been funded by the MoD or Department of Defence (DoD) and was, therefore, biased and invalid.<sup>3</sup>

The sheer amount of research about GWS and the number of specialisations involved are overwhelming. How is one to make judgements about truth and reality when there is so much information and when that information is so often contradictory? Even amongst those findings accepted by the expert paradigm there are anomalies and contradictions. For example, when Rook and Zumla published a paper in the much-respected *Lancet* (1997) that suggested that GWS might be the result of a Th2 cytokine shift induced by the combination of multiple vaccination, stress and the use of the pertussis vaccine as adjuvant, it appeared a plausible explanatory model had been found. However, it was quickly pointed out that this was only a theoretical

2. Although people may appeal for the involvement of outsiders (ie non-partial scientists), there often remains skepticism as to their neutrality: Will they, for example, be co-opted? Therefore, pleas for such independent expertise is largely unmatchable with people’s view of the reality of the situation.
3. This, of course, puts my own work in a difficult situation as the veterans were aware from the outset that I was part-funded by the MoD and fully funded by the government (ESRC).



case and so it could not be taken as a definitive finding. When other studies similarly reported a link, problems with methodology were cited as the findings were the result of a possible hidden bias. In other cases, it is the person's background or funding which throws their findings into question. For example, despite being widely considered a respected scientist, Hayley's work was often dismissed not only on the basis of methodology, but also because of his funding source. The battle is fought not just between who has a right to be heard in scientific circles – with some scientists and other voices being silenced or ignored – but there are also battles *within* the accepted scientific authority.

Both Bauman and Giddens draw attention to the way in which problems in science are broken down into their particles, each of which becomes the focus of specialised research. This is certainly the case with GWS. Given the sheer range of possible causes and plethora of outcomes (symptoms and illnesses), the problem is broken down into numerous specialised research subjects. This is felt acutely in the GWS case as researchers from various backgrounds waded in with their particular area of expertise to focus on some tiny element of the problem. This process of specialisation is paradoxical, for “the more minute the processes, the fuller the knowledge” and yet knowledge won in this way is “available not as illumination, but as issue-bound instruction. Partial knowledge belongs to partial specialists” (Bauman 1992: 21–22). Such specialist knowledge is difficult to share with others, indeed there may well be no effort made to make such knowledge accessible: “it is always the property of the experts, who administer its apportionment” (Bauman 1992: 21–22). The result is that the language becomes increasingly specialised and difficult to understand without that particular area of expertise. Knowledge is contained within that particular area or discourse. Each focus becomes divided off and there is little communication between those working on different aspects of the GWS case. Of course, this makes it difficult to navigate through the plethora of information and to gain an understanding of the bigger picture. The “more a given problem is placed precisely in focus”, through the process of breaking it down into particles, “the more surrounding areas of knowledge become blurred for the individuals concerned, and the less likely they are to be able to foresee the consequences of their contributions beyond the particular sphere of their application” (Giddens 1991: 31).

Debbie introduces Malcolm Hooper, a professor emeritus of medicinal chemistry, in her discussion (15). Veterans see him as *the* scientific expert of their condition, saying he looks at the bigger picture. In many ways this man is the driving force behind GWS and plays a central role in veteran's scientific understandings. Whereas other

scientists only look at GWS in relation to their small specialty, Hooper as a chemist can understand and discuss all the various aspects of GWS. Veterans often say that they trust Hooper and defer to him for all GWS information because they feel he is able to engage with all the subspecialties conducting research on the subject. He is seen by the veterans as being able to speak authoritatively on all aspects of the GWS research protocol. As a medicinal chemist he emphasised the interactions between the various exposures and aspects of GWS. He is seen as being able to make connections between the smaller specialised foci and bring them together to create an overall picture of GWS. He is revered, in part, because of his ability to respond to each particle of research and organise them into a grand narrative of the syndrome. In other words, he has a more holistic view of the condition and communicates this to the veterans.

Hooper is the veterans' scientific advisor, spokesperson, expert witness and president. He is the most trusted and most involved advocate and I saw veterans treating him with a heady mixture of respect, reverence, admiration, loyalty and love. His word is gold and unquestioned by the veterans, but he is a source of scorn and annoyance for others. Much of the veterans' information is acquired via Hooper. He is the champion of the veterans' cause and he positions himself against other researchers who are perceived as dishonest and involved in conspiracy (19, 30, 31). As John said:

Misinformation, disinformation. The largest group of doctors that have produced evidence, or so called evidence, of Gulf War related illness has been at King's College/St Thomas' and that investigation has been funded by the DoD. And they've funded the investigations that they want. They didn't want them to look. The MRC have not granted proper funding. [A doctor at Sheffield] told me, he said, "any doctor that has put proper bids in for proper research into the illness were turned down. The only people that were granted funding were King's College. And that was a psychiatrist there." So they had already channelled the funding into the direction of where they wanted it to go and that was done by the MRC. Now, they've already chosen the route that of epidemiology, which is the furthest from looking for medical illness or a problem. And it's usually a way to somatise illness when the government don't want to accept responsibility.

Thus, the biased and political nature of scientific studies is emphasised. Both Mark and John suggest that UK studies are inherently flawed because of their funding sources. John, with one broad, brush stroke, dismisses all the work by one influential UK research team because of their specialisation of psychiatry and epidemiology. Knowledge "always lacks. Ambiguity always lurks. If you want to cast blame, there are

always loopholes for reading the evidence right” (Douglas 1992: 9). The consequence of using science in politics is that “both sides consult their own scientific experts. Huber (1990) describes how fringe calls to fringe: peripheral movements take technical advice from peripheral science and force a split between centre and frontier”. By so doing, science loses its power” (Douglas 1992: 33).

## **Claims to Truth and Knowledge**

This research raises important ethical issues, particularly with regard to the struggle over truth and knowledge. Paine’s study of the Saami during the aftermath of Chernobyl (1989) shows the way in which struggles can appear over claims to knowledge. Deconstructed by the various parties quite differently, what “Chernobyl” throws into relief “is a competition between two kinds of knowledge, each with its own source: the experts’ and the practitioners’. Each makes a claim of ‘understanding’ knowledge, which excludes the other party” (Paine 1989: 140). Similarly, what I witnessed was a struggle between various parties to gain legitimacy and authority for their particular perspective and theory about the illness. Of course, claims to truth and knowledge were intimately tied to political, economic and social positioning and gains. We must remember that the expert, no less than the layperson, reaches his or her interpretation via ideology. A government may stake its own path, or it may move gingerly between expert and layperson. Indeed, I wish to point out the way in which all parties negotiate knowledge and expertise and to emphasise how much contradictory information abounds between various specialists.,

The image of western science as pure, independent from politics, has been challenged in recent years by anthropologists. Nader (1996) draws attention to the central role boundaries play in power relations. She reminds us that the boundaries of science are drawn and redrawn and that borders are often contentious. The political nature of science is clear in the GWS debate. Certain boundaries have been closed off with only some experts being seen as able to comment legitimately on the condition. Biomedicine and epidemiology have bracketed off the discourse and become its gatekeepers. Certain perspectives and theories are dismissed outright by those in power.,

When comparing African thought to science, Horton (1967) claims that the former is not reflective or critical, is closed rather than open, unable to entertain alternative conceptions to its dogma, and ignorant of the experimental method and the concept of chance. It resorts to secondary rationalisations to protect its premises, rather than

courageously face the possibility of falsification. Tambiah suggests that Horton's interpretation of Western science is ignorant of the way it is protective and closed: "Horton would certainly have been chastened had he encountered Kuhn's presentation of the conventional stratagems employed by the practitioners of contemporary normal science to keep their thoughts intact" (1990: 91). Within science the idea of a "single world" is being challenged. Overing points out that both Kuhn (1964) and Feysbend (1975, 1978) have argued "against the belief of Western science in a unified objective world unaffected by the epistemic activities of the scientists themselves; rather, they say, the world, from the perspective of our knowledge of it, is how we view it through the paradigms we create" (Overing 1985: 2).

One "could argue that the demarcation of science is part of a general tendency to establish formal structures through which we think about the world, whether it be in terms of science, medicine, or art. But the demarcation of science – a keystone of modernity – is of particular interests in arguments about boundaries and power" (Nader 1996: 2). In 2004 the Lord Lloyd Inquiry called for the MoD to accept GWS as a unique biomedical phenomenon. The medical community and the MoD argued that the inquiry, and Lord Lloyd in particular, were not in a position to make medical judgments. Arguing that the inquiry was merely a review of existing literature, the expert science paradigm suggested that nothing new had been done and thus no change to the categorisation was necessary. Those who are in the position of categoriser are in charge of producing hierarchies of privileged knowledge. Nader points out that the process tends to "fix a positional superiority in the mind of the categorizer – the notion that one is superior by virtue of being in a position to create categories, or to draw the lines" (1996: 2). Again we see how boundaries around who can and cannot classify and categorise illness categories have biomedicine acting as gatekeeper. As Nettleton points out, when it comes to making sense of abnormal bodily experiences medicine controls the means of production of knowledge of bodies. People "who live with illness that lacks any biomedical explanation form an extreme instance of the experiences that people face more generally in contemporary society. They are the embodiment of the risk society" (2006: 5).

Throughout history there have been different ways of seeing and understanding the world and yet now science dominates all forms of human knowledge. Science "is not only a means of categorizing the world, but of categorizing science itself in relation to other knowledge systems that are excluded" (Nader 1996: 3). Modern "science makes knowledge scarce because it asserts unrivalled hegemony" (Alvaras 1988 in Nader 1996: 12). We should be aware, however, of the presence of

science outside of the “expert science” paradigm. Anthropologists (Jacobsen and Ziegler 1996; Martin et al. 1996) reveal the importance of including forms of knowledge and viewpoints that lie outside the gates of expert science. Indeed, there have been cases when experts were wrong and popular delusion was more accurate than scientific facts. Looking at the process of US detection of Russia’s first atomic test, Jacobsen and Ziegler (1996) show “why scientific beliefs should not be canonized” and argue for the “importance of non-expert knowledge in key public policy decision making” (Nader 1996: 22). Of course, it is important to remember that boundaries are often blurred and knowledge flows between different realms: from expert scientists to lay people, and vice versa. Different parties and institutions are influenced by one another. Veterans and GWS advocates negotiate and absorb scientific and expert knowledge, just as the scientific discourse is influenced by lay perspectives, veteran’s experiences and theories, as well as by the media more generally.

The role of the media in the construction of this syndrome, by disseminating information and adding validity to certain assumptions and tropes, is central to the development of GWS. Almost all of my informants reported that whilst they felt “not themselves”, they did not realise what was wrong with them until they saw or heard a media report about GWS (see Chapter 5). As one commentator on GWS suggested:

[It] is easier to imagine plots than to deal with uncertainties, and more exciting to whip up emotion about enemies within than to contend with the confusion and anxiety of social change. TV and print journalists have played a significant role in escalating anxieties and exacerbating distrust, by playing up suspicions, playing down evidence, and publishing the unproven – and highly disputed – hypothesis of a few doctors. (Showalter 1997a: 25)

Of particular interest is the divergence between scientific knowledge and the information reported by the popular press.

The media plays a dominant role in forming and shaping the discourse surrounding the disorder. It has chosen to stress certain aspects and has used certain studies to emphasise its stories. There is a huge discrepancy between the popular press and scientific reporting of GWS in both quantity and content. The number of media articles both preceded and exceeded any professional evidence on the subject. This media reporting of GWS was not a response to, nor was it dependent upon, professional publications. The themes that emerged with the disorder cannot be traced to scientific or medical research. GWS appears to be an example of the non-medical press setting the agenda for the medical press.

It would seem that scientific and medical research reflects the lay-derived themes of GWS. McKechnie (1996) suggests that science and its practitioners are not the only actors in the construction of scientific authority. Paine's research with the Saami and Wynne's study of Cumbrian farmers showed how these groups' own, specialist, practical knowledge was a cherished part of their identity. Paine expresses clearly how the Saami came to feel that dependence on expert knowledge undermined their cultural identity (1987, 1992). While the Snasa "needed the scientists' knowhow, they knew that they *must not surrender to it, must not allow their own knowledge and understanding ... to be deligitimated*. For were that to happen, it too would be a mark against their culture" (Paine 1989: 140; emphasis in the original). For GWS sufferers, knowledge of scientists was central to their movement as their battle for legitimacy was waged within the boundaries of biomedicine. Their struggle was for biomedicine to acknowledge their illness as an organic disease entity, which could only be done using the tools, methods and theories of biomedicine. In this case the struggle over knowledge was about *whose* scientific knowledge could be deemed legitimate.

Paine and Wynne describe situations when participants were excluded from formal decision-making, which served only to strengthen the boundary between "us" and "them". However, these situations differ dramatically from that of the Gulf case, where decision-making bodies include veterans themselves. Furthermore, veterans' identity seemed to be wrapped up in being able to "beat scientists at their own game" using medical language. For example, they claimed that "many veterans are medically trained." So, in the Gulf case, expertise is held by veterans' own knowledge of their bodies and experiences, but they seek more and more scientific knowledge to increase their expertise. Furthermore, some veterans, such as association leaders, are seen as the ultimate authority due to their medical background, individual experience, and scientific knowledge gained through studying GWS.

Wynne showed the way in which Cumbrian farmers explained the "the lack of credibility of the present scientific claim about the Sellafield-Chernobyl distinction as due to the untrustworthy way in which the experts and authorities had treated them over the 1957 fire" (1996: 31). Their reading of the present was embedded in their perception of the long history of misinformation surrounding the site. Similarly, veterans point to a long history of untrustworthiness, secrecy and cover-up of the MoD to situate their understanding of GWS, often linking the present situation to Porton Down and the experiments done there. For a veteran ready to suspect the MoD, there were

situations of cover-ups or gaffes in the war which provided them with ammunition. For example, in the autumn of 1996, Nicholas Soames, Britain's armed forces minister, was forced to admit that the House of Commons had been misled about the use of pesticides in the Gulf, and that such use had been far more extensive than anyone had said. Similarly, the Khamisiyah incident was not made public knowledge until years after the war. Whether this concealment was deliberate or just a result of bungling is not clear, but it damaged public confidence. Interestingly, the Cumbrian sheep farmers that Wynne spoke to linked their mistrust of Sellafield with the fact that it had been an MoD site at the time of the fire and, thus, shrouded in secrecy. The MoD seems to be regarded as a mysterious and malevolent institution; the veterans' perception of it as such is neither unique nor new.

## **Levels of Causation**

Causality has provided an important set of debates in philosophy, with Hume arguing that the imperative to construct tangible causes is an important aspect of what it is to be human. Anthropology argues that to classify is as much a moral as an intellectual process. Cohn (2000) suggests that since ideas about how things can happen are based on beliefs about how they happened in the past, risk perception must be examined in conjunction with theories of causation. This has long been an important theme in medical anthropology, drawing on Evans-Pritchard's idea that Western science answers the "how" but not the "why" questions. As Evans-Pritchard explains, "Every Zande knows that termites eat the supports [of the granaries], [but] why should these particular people have been sitting under this particular granary at the particular moment when it collapsed?" (1976: 22). Thus, although practical reasons explain the immediate causes of illness and misfortune, the Azande turn to witchcraft to answer the "why me?" question, to find an underlying cause in the moral universe and a response that is socially embedded and morally satisfying. Evans-Pritchard describes the boy who hurts his foot on a stump, the cut of which subsequently gets infected: as a "conclusive argument for his view he remarked that all cuts do not take days to heal but, on the contrary, close quickly, for that is the nature of cuts. Why, then, had his sore festered and remained open if there were no witchcraft behind it?" (1976: 20). This was to be regarded as the Zande explanation of sickness. Such an explanatory system can be seen as similar to Gulf veterans' understanding of their illness.

Through the explanation of GWS, all experiences of misfortune and illness are linked together and made intelligible. Remember the veteran introduced in the Introduction who saw the ultimate cause of his injured leg as GWS. In other cases veterans would say that they had cancer, but that cancer did not run in their family or they thought it was “rare” for them to get it. Thus, they concluded that they had cancer due to the exposures in the Gulf. Others might say that their illness “was in them” but it was triggered by the Gulf exposures. Thus, they would not have actually become ill if they had not been to the Gulf. Similar to witchcraft philosophy, the real cause need not be excluded. Cohn notes that the process of establishing “clear causes is a way of keeping the past and the present reasonably tidy” and is thus a way of ensuring order both cognitively and morally (2000: 218). There is often growing lay frustration with scientific explanation; people experience the dissipation of cause and thereby the disappearance of an elementary moral resource (Cohn 2000).

Cause is the central tenant of GWS. It is the cause – the complex of exposures – which is the key to the illness, not the clinical type or symptom presentation. What the veterans have in common is cause: the Gulf War. Of interest is the way in which cause does not work in the same way in veterans’ theories as it does in the medical system. Lewis’ (2000, 1975) work on the Gnau showed how it was a diagnosis of cause and not the manner or clinical type of illness (Lewis 1975) which was their focus, in a similar mode of thought as that found in GWS explanatory models. Similarly, the person is either considered ill or well and the specific locale of the illness is unimportant. Furthermore, the “decision about whether someone is ill as a whole is largely left to the individual concerned ... This contrasts strikingly with the way in which the final decision is held to rest with medical experts in our culture” (Lewis 1975: 333). Each individual in the Gnau “system” views their own case with concern for particular detail, with generalisation being less important. I found in Gulf cases that it is the commonality of a link to exposures which holds the GWS system together. Although veterans claim similarities between cases, they are not actually concerned with specific generalisation. There is a huge flexibility accorded to difference and individuality, due in part to the large complex of exposures and individual uniqueness which allows for infinite possibilities.

The picture presented in this chapter is one of inconsistency, a mercurial model which rational science would deride. Central to this discussion is the issue of rationality. Winch (1964) challenged Evans-Pritchard’s contention (1934, 1935, 1937) that Azande beliefs about witchcraft and oracles are logical but mistaken. The predominant



position within anthropology has been against Winch and with Evans-Pritchard: that Azande beliefs are fictitious, though as logical in argument as those of Western science (Overing 1985). The conviction that the West is highly rational has begun to be scrutinised, particularly given the crisis of faith in science. Wynne suggests, “The ‘rational’ approach championed by modern scientific culture would assume inconsistency, imprecision, or ambivalence to be manifestations of intrinsic feebleness. However, we begin to see that such absolutist categories are actually moral or cultural stances” (1996: 41). Furthermore, what is revealed:

[I]s a deeper and more complex consistency in public reasoning than that recognised by such simplistic models. In the real world people have to reconcile or adapt to living with contradictions which are not necessarily within their control to dissolve. Whereas the implicit moral imperative driving science is to reorganise and control the world so as to iron out contradiction and ambiguity, this is a moral prescription which may be legitimately rejected, or at least limited, by people. They may opt instead for a less domatory, more flexible and adaptive relationship with their physical and social worlds. In this orientation, ambiguity and contradiction are not so much of a threat, because control and manipulation are not being sought or expected. This is no less legitimate a form of rationality than the scientists’. (1996: 41)

Lewis reveals that Gnaou systems of knowledge and belief are “not ordered into a flawless unitary system” so explanations of illness do “not have to be accommodated to one single line and sole original source” (1975: 352). The “variety of bits and pieces of possible evidence, the selective attention given now to one facet of the situation, then another, permit multiple explanations for the same illness along different lines of reasoning” (Lewis 1975: 353). In this system, consistence, uniformity and singleness of explanation are not prized, while conditions of proof and disproof are not clearly established. Aristotle spoke of different chains of causality,<sup>4</sup> there being different explanatory frameworks for the same thing. In each culture, however, we value some more than others because we are trained to do so. If one is not satisfied with the lack of meaning, we are able to carve out another one, which is just what veterans do.

Medicine is strict, but humans are faced with the nebulous. The veterans make a claim for causality that is not only or strictly

4. I am indebted to Simon Cohn and the rest of the Genomics, Anthropology and Technology Group for this foray into levels of causality.

biomedical. They want to dictate what *they* think is the causality of their individual case. In many ways their view of the world is similar to belief systems of other societies, where it is normal for truth to be tied to other truths that are social, moral and political in scope (see Gellner 1973). Veterans create chains of causality where everything is linked together and has overall meaning. For example, one veteran I met suggested that DU had caused him to have liver and kidney problems and went into great detail about how he had come into contact with DU as a result of picking up charred Iraqi bodies on the Basra Road. I was surprised by his suggestion that his liver problems were due to DU because he had just spent the past hour telling me about his experience of being an alcoholic, living on the streets for years after the war. He did not, however, link his years of heavy drinking to his liver and kidney problems because, as he said, his drinking was secondary. He said in retrospect he realised that he drank to deal with the GWS and, thus, it could not be the cause of his health problems. He creates a causal chain where the GWS, caused by DU and other exposures comes first, with drinking being a response to this. Veterans fashion out an explanation in a way that makes sense to them and makes sense of their experiences both as an individual and as a group.

All roads lead to GWS. All the separate and various symptoms and illnesses are part of a causal chain. Mark points out that many of them have CFS (19), but that is *caused* by GWS. Similarly, veterans describe psychological symptoms as *caused* by GWS: they are either chemically induced, a secondary result of their illness, or the result of their illness not being acknowledged. Thus, the very fight for recognition feeds into their theory of causation. There is a real desire for a meta-narrative that links everything together, ties everything up and responds to every criticism. Mark, for example, incorporates an chemical element to make sense of the fact that there are so many symptoms, so many degrees of severity, and that people have become ill at different times (15). For Mark, age, fitness and vulnerability are all linked. As will be discussed in Chapter 4, the immune system plays a central role in this flexible and inclusive, yet robust theory of GWS.

GWS theories are extremely accommodating, with the possibility of including different illnesses, or matrices of illnesses for each individual. They can envelop any social issues (adultery, criminal behaviour), any psychological problems (PTSD, depression) as well as any disease (cancer, MS). They are also able to contain a variety of different (and possibly contradictory) theories of specific causation. GWS theory can include a number of individuals: including those who were not deployed. The GWS system of thought is open to new findings and emerging beliefs in the world. It is a very robust system, accommodating

to a fault, yet also able to deflect criticisms or evidence which apparently contradicts it. In light of the former it is an open system, yet in light of the latter it is closed.

Evans-Pritchard illustrated how beliefs in witchcraft, oracles and magic accommodate and absorb experience that appears to show them to be invalid. Situations of this kind are explained as due to a breach of taboo in preparing the oracle-substance which makes a false detection, so that each apparent failure is rationalised in terms of other mystical beliefs. Thus, the whole system is bolstered by apparently contradicting evidence. The system itself is constructed so that it appears to accord with reality and is insulated against apparently contradicting evidence by secondary elaborations of belief and the limited perspective which any one man has on the setting of witchcraft accusations and magical operations. Evans-Pritchard's study "of how Azande beliefs in witchcraft, oracles and magic operate as a self-sealing and self-supporting system is so acute that Polanyi used it as a model to examine 'the stability of beliefs' in science" (Gluckman and Devons 1964: 161). Similarly, GWS is a flexible yet closed system which was able to deflect any criticism or information which might dispute it. For the Azande, there was always an explanation for why things did not work. Similarly, there are layers to the GWS explanatory system. As mentioned specifically in terms of Haley's theories, veterans use parts of some theories whilst ignoring others. They also hold contradictory theories at the same time. It was as though when they spoke about one exposure or its associated theory they did so in isolation of the other theories they presented. As they argued for one theory, the others fell away.

One of the main ways the GWS system of thought is able to deflect information which contradicts it is by recourse to a grand conspiracy theory. According to the veterans the world of science is divided into two main groups: those who support the system of thought, characterised by good, honest, independent scientists; and those who dispute the reality of GWS, characterised by evil, self-serving individuals who are funded by and, therefore, under the control of the MoD. So, for example, the fact that the majority of scientists who supported the GWS movement are unpublished, could not get their findings published in peer-reviewed journals, were disrespected by the scientific community, fired or struck off the General Medical Council was not evidence of their inferiority as scientists. Quite the contrary, it suggested a widespread conspiracy which pointed to the fact that their work was getting dangerously close to the truth. The details create the need for a plot. The founding practice of conspiratorial thinking is the search for the missing plot (Stewart 1999).

## Meta-narrative

GWS and other new illness movements provide a template, a way to construct inclusive biographical narratives. It would appear that people reach for explanations that tie up loose ends and are able to incorporate a wide variety of experiences. It would seem that people are striving to construct a meta-narrative. Tied in to this process, particularly with regard to GWS, is the reliance on conspiracy theory. As Stewart suggests, the details in one's experience create the need for a plot: "It's not that for conspiracy theory everything is always already a rigid, all too clear plot, but rather that the founding practice of conspiratorial thinking is the search for the missing plot. Think of it not as a prefabricated ideology ... but as practice" (1999: 15).

Furthermore, it is a "system that makes sense of inchoate sensibilities and moments of strange convergence. It's practice born of a world that cries out for interpretation" (Stewart 1999: 16). Stewart reveals that conspiracy theory is a means of constituting reality where everything is connected and the connections are uncanny. In "isolation, any one of these 'grains of salt' would not seem significant. It is the cumulative effect which is powerful, provoking new mappings of how the world works and new logistics for explicating where trust should be located" (Fortun 1999: 346). GWS is characterised by consuming doubt, whilst there is also the unbending assertion that truth will come out, conspiracy theories combine such doubt and belief that the truth is out there (Stewart 1999).

Writing specifically about conspiracy theories and GWS, Fortun states that they "have not been provoked by any one traumatic or especially noteworthy incident. Instead, veterans have heard news stories, exchanged memos across the Internet, and, occasionally, met other vets with whom they could share stories. Theorisation of conspiracy has thus been gradual, cumulative, and often via indirection" (1999: 346). She sees that conspiracy theories in this context have been "provoked, produced, and made to function", in order to respond to the strange and often contradictory information that circulate around the illness.

Hofstadter wrote of conspiracy theory:

The typical procedures of the higher paranoid scholarship is to start with such defensible assumptions and with a careful accumulation of facts, or at least of what appear to be facts, and to marshal these facts toward an overwhelming "proof" of the particular conspiracy that is to be established. It is nothing if not coherent – in fact the paranoid mentality is far more coherent than the real world since it leaves no room for mistakes, failures, or ambiguities. (1952: 36 in Marcus 1999: 1)

The work (Fortun 1999, Marcus 1999, Stewart 1999) on conspiracy theory mentioned above was a contribution to a recent book edited by George Marcus, which looked to deepen and amend Hofstadter's study "by coming to terms with the paranoid style, not as distanced from the 'really' rational by exoticised groups with which it is unusually associated in projects of targeted critique or exposé, but within reason, as a 'reasonable' component of rational and commonsensical thought and experience in certain contexts" (Marcus 1999: 2). In his introduction to this work, Marcus suggests that the cold war era was a broad context and condition of contemporary life that made the paranoid style and conspiracy theories an eminently reasonable tendency of thought for social actors to embrace. Furthermore, "the legacies and structuring residues of that era make the persistence, and even the increased intensity, of its signature paranoid style now more than plausible, but indeed, an expectable response to social facts" (ibid.). He also suggests that the crisis of representation, with its accompanying inadequacy of meta-narratives and conceptual frames to explain the world provided the context of social actors reasonably embracing conspiracy theories.

This system is layered in that it deals with chains of causation. It is also a moral system in that it makes sense of responsibility and enables the sufferer to appoint blame clearly. The GWS system is flexible, able to incorporate a huge variety of internal difference: different experiences, divergent symptoms, and a magnitude of often-contradictory theories. It is adaptable, able to incorporate and encompass new findings and directions. However, it is also a closed and watertight system, like the Azande system, in that it deflects criticism and is able to respond to information which looks to contradict it.

## **Conclusions**

Veterans see the world of science as divided into two groups: those good, honest scientists who support them; and those biased scientists who do not support their cause, are part of an MoD conspiracy and are dishonest, evil people. Despite this view of science as being distorted by scientists, they maintain an immovable faith in the importance of science and believe that true science will eventually reveal their illness and its cause. They raise important questions about authority and knowledge and the right to speak and to be heard. The story of GWS is foremost a struggle over truth and knowledge: who is considered an expert and whose theories are taken as fact? Indeed, whose account can be seen as a true representation of reality? Despite their accounts and perspectives being absorbed and legitimated by the media, the

veterans and their advocates are dismissed by the expert scientist paradigm. There are also struggles over claims to expertise within the scientific community, though, with boundaries being drawn and guarded. A number of scientists, who support the veteran's cause, are seen as maverick and their methods, theories, expertise and academic background are called into question by other experts.

There are levels of causation to the GWS explanatory model, allowing for a great deal of flexibility. Veterans' theories are an attempt to find meaning in their experiences and a way to tie up loose ends. GWS theories of causation are moral systems: they point the finger at those who are to blame for exposing sufferers to risk. The flexibility and robustness of the system allows veterans to map their individual experiences onto the overall explanation. Through GWS theories of causation veterans are able to construct a meta-narrative that relates seemingly unconnected experiences, illness and misfortunes.

## **Part II**

# **BODIES AND BOUNDARIES**

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## Chapter 3

# LEAKY BODIES

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### Introduction

The taxi took me from the train station in Skegness to the family resort, my home for the next week while I attended the GWVA's Annual General Meeting and respite week (AGM). There was something odd about bringing all these ill people together to a holiday camp to discuss and dwell on their suffering, yet the depressing surroundings of a Butlins holiday camp in the middle of a cold and grey March seemed to match the mood. I was ushered into the lobby of the meeting building where I saw Rebecca, John, Jack, and other familiar faces. They had set up a table with association badges, pins and information. The lobby was full of people milling around, drinking coffee and chatting. Children ran in and out of the playroom as their parents caught up and discussed the latest GWS information. I registered with Rebecca and was given a "welcome pack" and my room key. I set off to get settled in my room and looked through the welcome pack. The pack contained an itinerary for the week outlining talks (speakers included Malcolm Hooper; Dr Jones, a psychiatrist involved in the movement, and the lawyers representing the case against the MoD), information sessions as well as nightly entertainment. Information about the illness and symptom lists was included, as were various scientific papers.

After pouring over all the information in the welcome pack, I returned to the lobby. People were arriving, signing in, paying their yearly membership fees and then chatting to one another. As I absorbed the scene I saw one man leaning on two wooden walking

sticks and a number of others, each aided by one walking stick. I sat down on a couch beside a man I did not recognise. Soon after a woman approached me, asking if I was “the anthropologist”. When I told her I was she pulled out an appointment card and asked if she could sign her husband up for an appointment. After arranging the details with her, the man beside me introduced himself. Ed and I sat talking for some time. He explained that he felt a bit strange being here because he was not sure if he fitted in, as he had not fought in the war. Stationed in Cyprus in 1990, Ed had been given the inoculations in preparation for the Gulf War, but in the end was not deployed. Having not had much contact with the veterans’ association and having never attended any gatherings of this kind, Ed was unsure of what to expect. Everyone seemed to know each other he mused, but he did not know anyone. Feeling very alone, he wished his wife and child could have come with him.

Ed was very easy to talk with and seemed like a nice, gentle guy. Well-mannered and pleasant, he immediately spoke about his young son of whom he was very proud. He began to tell me about his life and his time in the army. After five years in the army, he left in 1992, soon after the Gulf War. Joining the army at 18, he had trained as a tank crewmember, but always knew that he was not going to make a career of it and left once his minimum service was up. In the last year of his service he had become disillusioned with the forces. He had broken his leg, yet he was not allowed to fly home. He had just had enough, so he left. The next year he began experiencing symptoms, including eczema and glaucoma – the latter concerned him as he was only 31 years old, and he had green discharge out of his eyes. He began itching all over, became irritable and noticed aches and pains in his joints. He also felt he was having palpitations, breathing problems, as well as experiencing pins and needles in the tips of his fingers and toes. One of the more distressing experiences was that his hair fell out and only grew back before his wedding in 1999.

Ed painted a picture of himself as a super-fit army soldier who played football. Yet now his immune system was shot, he explained, and he “got everything going”. Ed met his wife a few months after leaving the army. She had noticed a change in him, he said, in that he had mood swings and become a perfectionist. Other things had worried him and made him feel as though something was wrong. He said he had Burning Semen Syndrome and was sensitive to sunlight. His wife began to get a lot of thrush and sadly, had a miscarriage which had occurred because his sperm “attacked her egg”. They had since had a healthy boy.

The list of symptoms from which Ed suffers is typical of GWS sufferers. In this chapter I will discuss veterans' symptoms, particularly in order to investigate their understandings of risk and their bodies. Veterans' complaints invariably concern themselves with anxieties about the body, body boundaries and bodily vulnerability. Body substances are imbued with meaning and power; they contain the toxicity of the Gulf War exposures and are dangerous because of their ability to traverse body boundaries. Most body substances are involved in discussions about GWS: spit, sweat, semen, urine, faeces and blood are all important for their role as symptoms, as markers of the illness and/or their role in contagion. A website<sup>1</sup> about GWS, for example, stresses its contagious character, saying,

[E]vidence is now turning up that doctors who treated GWS vets have contracted the disease themselves. Dr. Larry Goss of Walters, Oklahoma, never went to the Gulf, yet he and his wife are now sick. "We do know that GWS is transmitted by perspiration, saliva, and sexual secretions," he said. He added, "As far as I'm concerned, they [the government] just took a gun and shot it at my wife". (Marshall 1996)

In some reports beliefs about the toxicity of body substances is taken further, as some veterans have claimed that their vomit glows in the dark.<sup>2</sup> One veteran described his regiment as the first "glow in the dark regiment". Veterans also suggest that their body boundaries have changed; their bodies transformed as a result of GWS. Some say their bodies have diminished, losing muscle and bulk. Indeed, one of the veterans I spoke to suggested he had shrunk, a claim repeated by two veterans in Mississippi (Jaynes 1994 in Showalter 1997b). Others say they have become bigger by gaining weight, suggesting they have "ballooned". Thus, narratives of GWS involve discussions about shifting bodily boundaries as well as the permeable nature of barriers.

## Body Substances

### *Skin*

When I asked Ed which body systems are affected by GWS he listed a number, but suggested that his body system most affected was his skin.

1. <http://csf.colorado.edu/forums/peace/96/nov96/0107.html>, Thursday 21 November 1996, report by Carole Marshall.
2. Brian Martin is an American Gulf veteran who is known for his glow-in-the-dark vomit.

Common symptoms of GWS are skin rashes and other conditions played out on the surface of the skin. Napier notes, “particularly considering the extent to which problems of immunity manifest themselves *on the skin* – as the body’s inability to come to terms (in a sense that is *simultaneously* symbolic and biological) with the value systems as such: that is, with its environment” (1992: 151; emphasis in the original). Veterans suggest that their skin is more sensitive than before and that it often reacts adversely to the environment. There is a sense of change, as though veterans’ interaction with their environment has altered.

Ann, one of the veterans discussed in the previous chapter, explained that she had a number of symptoms, but their visibility was elusive: “I have increased chemical sensitivity. Can’t wear perfume, had to change deodorant. Rash, but the rash is not there when the doctor from War Pensions comes round.” Ann emphasises her sensitivity to chemicals and day-to-day products that many would take for granted, but she also points out the fleeting nature of the visible signs of this sensitivity.

### *Internal Surfaces*

Similar to the skin, surfaces of certain organs are thought to be inscribed with GWS. Veterans report that they have scars on their livers and kidneys and commonly suggest that such scarring is the result of DU poisoning. One day at the GVMAP they told me a patient was demanding to be tested for DU and was complaining that they were not recognising the scarring on his kidneys. “But he does not have scarring on his kidneys”, the doctor said. At a later date the doctors at the GVMAP were annoyed because the Gulf Veteran’s Illness Unit at the MoD had suggested the GVMAP investigate all 3,000 cases for renal and liver scarring. One of the doctors said that liver and kidney scars “are like a scar on your arm, it is the end of a pathological process”. Furthermore, scarring, he said, is not caused by DU or the other possible exposures. In normal practice, I was told, physicians never request ultrasounds to see liver or kidney scarring for the scar itself is of no clinical significance. Scarring causes no suffering, according to the doctors at the GVMAP, and thus investigations of them were unnecessary. For the veterans, however, scarring proved some sort of malevolent interaction – it was a way to make their illness visible.

## *Bones*

Veterans commonly understand their bones as being weakened through their participation in the Gulf. A common symptom discussed is osteoporosis and, as mentioned above, some have suggested they are shrinking. It is suggested that veterans' bones do not heal or set properly. A few days into the AGM Ed and I spoke again and I found he had re-interpreted an event in his life after meeting with other Gulf veterans. When I sat down with him to conduct a formal interview he had just met with a group of other non-deployed Gulf veterans and said he was amazed by how much they had in common. He said that as they spoke he mentioned what he thought was a normal rugby injury. The veterans pointed out that it was unusual for his leg to shatter as it did instead of breaking cleanly and told Ed that a symptom of GWS was weak bones, suggesting this would explain his injury. The previously innocuous injury took on a new meaning and was now encompassed into a diagnosis of GWS.

Bone is important for its ability to be tested; it contains a kind of narrative of exposure. It is seen as interpretable to some extent in relation to exposure to depleted uranium. Below, John, introduced in the previous chapter, discusses the role of bones in GWS. This narrative relates to his dismissal of the chemical weapons theory discussed in the previous chapter.

Again, go back to the bone disorder. The toxicity, we've been exposed to a toxic compound in our bones. So, it wasn't a nerve gas, because there wouldn't be enough to cause that. It would have been instantaneous type of health problem: death [laughs]. The vaccine problem, now that could have caused the degradation of our health. Our health broke down and as it broke down, we were not turning our bones ... and that could explain osteoporosis and those things ... the atomic effects. Slow and gradual physical and mental ... I believe that my health problems are from the vaccines and secondary depleted uranium. I can only say that because I've been tested by three labs and three labs have said that I have got U235 and 238 isotopes ... and my bone results show that I've had a toxic exposure. At least I can say now it's no longer just in my head. It's actually in my bones as well.

Bones and the bodies of veterans are seen as components that are available to be removed and scrutinised. Bodies of dead veterans are similarly seen as artefacts of war with the war experience etched in their bodies, ready to be interpreted. Hooper regularly calls for more and more testing for Gulf veterans:

The difficulty is that the levels of excreted uranium are getting so small that detecting them is going to be difficult. Some of them have got past the detection levels, so we now want other mechanisms of identifying damage from radiation. And there are two ways of doing this. One is by biopsy and autopsy material and a number of guys have had bone taken out ... I think it was, wasn't it? That's where depleted uranium goes into bone. Like lead, it finds a home in bone. The body puts it out of the way, the best it can – in bone. If veterans die and are prepared to have tissue taken from their bodies, their family are prepared to have tissue taken from their bodies we should find, I think, depleted uranium in lymph nodes, possibly in the lungs, as well.

Veterans' associations, advocates and scientists alike have suggested that bodies should be "left to science" so that more tests can be conducted. Even after death the veteran's body is a text to be read for the benefit of the group. There have been a number of cases where this has occurred; the veteran or his family sacrifices their body after death in order for it to be investigated.

### *Faeces*

Most veterans suggested that one of the parts of the body most affected by GWS is the bowel. Diarrhoea and Irritable Bowel Syndrome (IBS) are two of the most common symptoms reported by GWS sufferers. Jack, the veteran introduced in the previous chapter, said: "Bowels, I mean a lot of people's bowels are affected ... Even simple things that can be embarrassing ... that you don't realise that you soiled your underwear. Again, we all have that."

John, also present during this focus group agreed, and suggested that all sufferers have "irritable bowel". The common complaint of diarrhoea may be linked with experiences in the Gulf, as it is reported that many veterans experienced diarrhoea whilst they were in the Gulf, possibly as a reaction to NAPS tablets. George, an ill veteran who was involved in the veterans' association and had been one of its founding members in the early stages of the movement, describes the effects of the NAPS tablets:

And all the time we was out there we were having side-effects from the NAPS anyway. Mainly diarrhoea. Again it was so common in the hospital, that if you was in your section and someone come round when you weren't busy, wanting to come round and have chat, umm, and you weren't there, all your mates would tell 'em, that it's the NAPS. So they would know to find you in the toilet. That's how common it was.

I was struck by how often and openly veterans spoke about their bowel movements. Most described their bowel movements as irregular and as a source of concern. One veteran, William, told me that the first thing he noticed when he began feeling ill was that he felt nauseous, like someone had “kicked him in the testicles”. He said he had extremely erratic bowels “from which emanated bad smells, pus, blood”. William had been concerned because at that time he was going to the toilet eight to twelve times a day and could not control himself. Concluding these remarks, he reported that at that time he felt as though he had inhaled toxic fumes. It was as though his bowels contained this toxicity and were allowing it to exit his body. He later said,

Whether it was radiation, DU, whether it was chemicals, whether it was the NAPS that were still hanging on in my system, I don’t know, but I think things are getting flushed out. The body does rebuild and repair itself. That’s still no excuse for the government to be giving these things and not accepting the way I was after the war.

When he noticed the pain in his testicles and his erratic bowels, William suggested that he began to be concerned about the state of his health and his body, so he sought medical advice. He was not, however, satisfied with the care he received. The reason he gave for this dissatisfaction was that he had never been given a blood or stool test; thus, the doctor did not inspect the substances of his body which he felt were proof or markers of his illness and its related toxicity. He felt as though he had been poisoned and was angered that “proper investigations” were not done. He continued:

Life was pretty miserable. At this time I was very tearful ... I hadn’t given my situation much thought, I was just vegetating ... I heard about Blackpool<sup>3</sup> and drove up, enrolled in their organization ... I was feeling much better physically and mentally and started to make some noises. Blackpool stirred me up to go [back] to the Gulf Veterans’ Assessment Programme at St Thomas’. This was my second visit. At my first visit I was horrified – I thought they were going to help me. I was there for the greater part of the day. I had half an hour of testing and they did an ultrasound. They found that my left kidney was not visible and the other kidney was enlarged ... I was then told by the doctor that I was born like that ... I was a freak ... and that I was otherwise fit and to go away. I felt it was a noddy medical that I could have got at my local surgery ... so noddy it was silly ... I wanted to know more about the missing kidney. I found out that my

3. Here, William is referring to the GWVA AGM/ Respite week which took place in Blackpool every year.

problems were similar to kidney failure. My friend did research on this and found the link with kidney failure. One kidney is working and that is sufficient, that is what my local doctor said, but I wanted to know if I was born like this or if it happened more recently ... I found out that the only way to investigate is through internal exam and the doctor said that this will not benefit you ... I am totally convinced that my kidney failure happened because of the Gulf War. The Assessment Programme refuse to investigate and I think they should do. I wanted to do a DU test and was told "we don't do them on demand".

Again, William stresses his dissatisfaction with the treatment he received by the medical establishment. His dissatisfaction is linked to lack of investigation. It would appear that he wanted his body to be tested, scrutinised and interpreted. He wanted it to be read and wanted others to make sense of it; indeed, he suggested that he would be willing to undergo an invasive internal exam in order to discover the secrets his body holds. Through investigation the invisible, intangible nature of his condition would be made visible to the medical gaze. When the doctors refused he became angry.

Potential sufferers were regularly asked whether or not they had diarrhoea or other bowel problems, suggesting that problems with one's faeces indicated internal problems. The focus on faeces was reflected in Hooper's dealings with veterans. He would often ask about the state of their "guts", which was not surprising given his background and interests: Hooper became involved in GWS as a result of his association with the Autism Research Unit, Sunderland University. He links GWS to autism by way of an affected "gut function", and suggests that a marker of GWS was high IAg levels. Hooper links sufferers of ME, organophosphate poisoning and "other chemically poisoned people" through reported high levels of IAg in their urine. Such occurrences indicate a dysfunctional gut, he argues, and sufferers from these overlapping conditions show evidence of a "leaky gut", an increased permeability of the gut wall due to damaged membranes.

Hooper's leaky gut theory argues that:

[W]hen the gut wall has increased permeability, the opioid peptides (casomorphin and gliadomorphin) which would normally be excluded are absorbed into the blood stream, giving rise to diffuse symptomatology and systemic dysfunction. Inflammation of the gut is common among ME patients, as are allergic reactions to foods including gluten. The compromised gut facilitates the development of a gut dysbiosis which in turn can give rise to autoimmune diseases, with very significant and chronic damage to health. (Hooper 2003)



Hooper summarises that the IAg system involves the gut, the brain as well as the endocrine and immune systems, which suggests that “detoxification is essential”. Many veterans follow his suggestion and focus on “detoxing” the body and changing dietary habits, including removing dairy foods and gluten.

Often pictured in his wheelchair, Joe is a well-known veteran and high-profile advocate who has dedicated a great deal of time to studying the condition. He reports:

I try to drink eight litres of water a day ... To try to keep any toxins, depleted uranium as dilute as possible so I can hang on to my kidneys as long as possible. I eat a gluten free diet. I take vitamin C. [shows me jar] A natural chelating agent which will help remove DU and heavy metals from my body. The biggest exit route for DU is in the faeces. So I try to eat a diet which will produce as much bulk as possible without putting on weight ... Lots of fresh vegetables, low protein diet ... I try to go to the health spa – the heat is good for muscles and pain. Oedema to sweat out toxins. Been to Iraq as part of research to see medical effects. Saw leukaemia type cancers, cancer of the colon.

One can see from the above comments that faeces are seen as containing the toxins present in the veteran’s body. Veterans perceive their faeces as abnormal and irregular and, thus, as indicative of something wrong inside the body. Faeces are a way for the toxic matter to exit the body. Similarly, urine and sweat are substances that can pass toxicity out from the body.

### *Urine*

During the above-mentioned focus group, John said that other than the immune system, the systems most commonly affected by GWS were “bowels and bladder”. He suggests that all veterans have bowel problems and that “irritable bladder” was also an issue for many veterans:

Irritable bladder, many of us took the NAPS tablets. I was one who stopped taking it but I made the decision, but I was a senior NCO<sup>4</sup> and I decided I was not going to take them anymore and I stopped taking them. I didn’t tell anybody. The reason being for me was I was going to the toilet every twenty minutes. You could almost set your watch by it. And I did twelve on, twelve

4. Non-commissioned officer.

off so every time I got to my cot I'd be asleep ... had to get up all the time to pee. Most of us had buckets from the hospital because we were peeing constantly ... for many of us that never calmed down afterwards.

Jack added that this urgency that one felt during the Gulf remained: "I mean even now if you want to go to the toilet there is a certain period of time, you know, but if I have to go to the toilet, I have to go now. I have to go straight away." Many veterans report that they had an unusual necessity related to urinating. They also often suggest that a common symptom of GWS was a frequent need to urinate. Indeed, in GWS circles, when it was noticed that I would often excuse myself to go to the toilet, it was joked that I had contracted the illness. Veterans would sometimes describe their problems with urination as "leaking". When discussing urination and bowel movements veterans stress the uncontrollable nature of their need and often suggest that they had had embarrassing accidents. Their bodies behave in undisciplined ways, like children or the elderly.

Similar to other body substances, urine is seen as a substance which can be read through testing and will hopefully reveal the illness to the observer. As mentioned above, urine is tested for IAg, but is also related to the issue of depleted uranium. As John suggests:

DU certainly can't be ruled out because DU has been found in urine and if you're passing urine, DU ten years after exposure ... I've got scans of my kidneys, it doesn't take a great deal .... It does pass through your body in 48 hours, which would explain increase peeing all the time .... you were already feeling shit anyway because of the vaccines.

Thus, urine makes the invisible illness visible through testing. At the AGM one of the days was dedicated to talks by various people. In one of these talks, Hooper discussed the importance of urine for testing.

The point about DU is that if you've got DU in your urine now ... you were exposed to it ten years ago and you've had it inside your body for ten years. It comes out in low amounts; therefore, a low level is significant. It means you've got internalised body stores of DU, sitting away firing out all the particles. The radiation goes up with time ... Stays there for a long time, for years, possibly forever ... And so what comes out [is] low levels of depleted uranium. Where does depleted uranium come from? The Gulf War.

Once again we can see that body substances are viewed as evidence of problems in the body and are present to be interpreted.

## *Blood*

When discussing the war, blood is often discussed in symbolic ways. During our first meeting, Ken, the head of one of the associations, said that during the war you had to “bag up the blood-soaked land from where a wounded man lay because you were not supposed to spill Christian blood on the land of Allah”. Another veteran, Brian, reported seeing “piles of sand with blood coming through” in the Gulf. A healthy veteran, Andrew, explained that “a week before the land war started ... [troops were told] “you are going to have loads of blood coming through here, loads of casualties, loads of deaths, be prepared.”” The spilling of blood is, of course, a symbol for the act of war itself.

I first met Bob, a large, quiet man, as he prepared for his War Pension Tribunal. The day before his tribunal he came to the hotel to meet with Kerry – the wife of an ill veteran who is an association member – and Malcolm Hooper in order to discuss his case. Bob immediately produced a letter from the National Blood Service saying that they did not want him as a donor because of information he has given them. Bob said that there were a number of health and safety guidelines at his place of work and that one of these guidelines was giving blood. He said that when he went to give blood he was asked “normal questions” but then the woman had asked what he used to do. Replying that he had been in the army, the woman then asked if he was in the Gulf, to which he replied yes. She then said that they would not accept his blood. Other veterans similarly complain that they had tried to give blood but had been refused. They suggest that this pointed to some sort of cover-up and proof that their bodies and their blood are unwanted and toxic. Veterans say they wondered what was wrong with their blood.

Although the suggestion of a blood ban may sound like paranoia, this belief is rooted in truth. When veterans returned from the Gulf there was a concern about leishmaniasis, as several dozen US veterans of the war had come home with a serious form of this condition. Caused by a protozoan parasite endemic to the Gulf, this disease involves symptoms such as abdominal pain, fatigue and fever; in the worst cases the spleen and liver were found to be enlarged. The US Defence Department therefore banned blood donations by all active duty personnel who had served in the war. The ban was revoked in late 1992, when additional cases did not surface (Wheelwright 2001: 36). However, many veterans were not aware of the reasons for the ban and believed that their blood remained banned. Military personnel give blood regularly and often see it as an important element of their service. Martha, a Canadian veteran, similarly spoke of the blood ban

in that country. However, unlike the reaction in the US and the UK where veterans were angered by the ban, Martha is pushing for a total “blood and organ ban in order to protect our Canadian citizens”. A website<sup>5</sup> about GWS discusses the contagious aspect of the illness and suggested that the “USA war machine [was] coming home to roost – this time in your blood stream”. Furthermore, it states, “military personnel are prolific blood donors, but because they were told for years that their illness was in their head, GWS has contaminated the nation’s blood supply with ‘germs from a terminal illness’”.

In the previous chapter I described the case of Mark. When discussing his symptoms, the presence of blood (bleeding gums, ulcers, bleeding from the anus) is clearly a concern for Mark. Disputing the suggestion that her husband’s illness is psychological, Debbie said, “Spitting up blood et cetera, that’s physical. They can’t say it’s psychological. Joint pain, OK, maybe that’s the brain saying that it’s worse than it is. But not bleeding from your backside and a cough.” There is the sense that blood and other substances are proof, tangible and real: evidence of the ravages of GWS on the body and the pure physical nature of the condition.

In the previous chapter I also outlined John’s suggestion that the preventative measures given during the Gulf War were part of an organised experiment and that blood was central to the recording of this experiment:

To an extent at the end of the war there was a RAF medical unit going around from unit to unit and asking about NAPS tablets and effects, side-effects. Also, some of the units were bled .... Blood was taking off them after the war. While they were still there and some of the units were bled before they went out. So, particularly 205, for instance, the general hospital: that was bled before it went out. Bled after the ground war, before they all came back. To see ... what the uptake was on the vaccines ... at the end of it, which is an experiment. There is no two ways about that. That is an experiment.

Their blood is read, owned and controlled by the military. Injections allow the military to enter the body and blood tests are conducted to track those bodies.

Veterans perceive their blood to be toxic, yet it often hides its toxicity. Although veterans demand ongoing and numerous testing, blood often does not reveal their suffering by testing positive to

5. <http://csf.colorado.edu/forums/peace/96/nov96/0107.html>, Thursday 21 November 1996, report by Carole Marshall.

investigations. It can be viewed with ambivalence. As one veteran, Ben, explains, “I’d rather be shot by a bullet than have something like that, something coursing around my veins causing more trouble in the future”. Blood may hide toxicity, ready to carry it through the body and make the veteran ill at some point in the future; thus, it contains potential danger.

## **Body Substances as Commodity**

We have seen above how body substances are important as products of the body which can be tested. Some body substances, such as urine and bone are seen as readable body material. Other products of the body, such as spit, sweat and faeces are generally not considered in this way. The most important substance for testing is blood. Veterans’ body substances can be seen as valuable commodities for scientists studying the condition and they often appeal, along with associations, for veterans to make their bodily substances available for testing. Veterans try to maintain control of their bodily substances: they make their substances available to those they trust and deny them to those they do not.

Many discussions about GWS lead to discussions on blood tests and their results. I was astonished by how many tests had been done on the blood of veterans, but also at the fact that they demanded more testing. One of the main objectives at the AGM was the taking of blood from the attending veterans in order to test for squalene, the latest agent considered to be implicated in GWS. One full day was set aside for veterans to provide blood, while in the preceding days the organisers lobbied to get everyone to participate. On the day one large meeting room was set up with a table at the front. The room was constantly full of people sitting in the audience chatting while a nurse and doctor stood at the front taking blood from each veteran.

It has also been suggested that blood can be used to diagnose GWS. A website<sup>6</sup> discussing auto-immune technologies suggests: “In addition to helping identify patients with GWS, the discovery of anti-squalene antibodies might also provide a key to more effectively treating GWS patients. The presence of the antibodies in GWS patients indicates that the immune system is involved in the development of GWS.”

The future is seen in terms of future testing and veterans conduct an ongoing battle for more and more investigations. Body substances, they suggest, will reveal the truth. Veterans remain convinced that tests will

6. <http://www.autoimmune.com/GWSTest.html>.

eventually reveal the cause of GWS – reflecting the ultimate faith in science discussed in the previous chapter. If they are experiencing suffering and pain, the body's substances will reflect that. During one of our conversations Ed describes his unsatisfactory visit to the GVMAP:

So before I went down there I had abnormal tests. I was having blood tests every two weeks to monitor it. Umm basically I was at my worst. I wanted to commit suicide. I wanted to end it all. I was really at my worst. At the time I was under the Chinese doctor and the skin doctor. I was trying Chinese medicines, herbs and all that. When basically my blood pressure was high at the time. And I went down to, I mean this was right up to a couple of days before I went down to London with Jane. When I got to London all the tests, the blood everything, was normal. They said nothing was wrong. I mean they said I didn't have high blood pressure. I mean, two days before I went down I had high blood pressure. Now surely, if you are anticipating getting loads of tests you do get quite frightened, if you are going to see a needle going in you. Your blood pressure is going to go up and mine was normal. You know, there was no reading, it was normal. They put gamma globulin abnormality reading down to alcohol. Umm, I mean I can go without alcohol. I don't need beer.

Although veterans demand ongoing blood tests, there is some anxiety about who maintains the blood and the results. Ken was sceptical of the GVMAP and said that they, along with the War Pensions agency were "still taking masses and masses of blood". Ken questioned why this was so. He also reported that these institutions took blood, body scans and X-rays and he felt that the veterans should get all the information, but he believed that the MoD was keeping all of it. Similarly, during a focus group a number of veterans complained that the GVMAP had taken a lot of blood, but denied taking any. One veteran said, "They take more and more blood and urine, but you don't get the results of the tests. So why are they asking you down two or three times, if there is nothing wrong with you?" A few minutes later another veteran expanded on these concerns and suggested that the government had known about GWS for years and that Porton Down was somehow involved: "I put money that the blood and urine from the MAP goes down to Porton Down. The Wiltshire police are investigating Porton Down." These veterans suggest that their blood is being used, tested and filed secretly as part of some monitoring system or experiment.

## Visibility

A common complaint is about the invisibility of the illness. Veterans and their advocates emphasise that because their illness is internal it is not acknowledged. The invisibility of their illness was contrasted with the more obvious condition associated with war: the amputee. As Kerry suggests, “had they lost a limb everyone would be sympathetic”. Another veteran, Paul, explains: “People don’t understand GWS because you look OK. The problem with GWS is it’s internal: the nervous system, muscular-skeletal. It’s not like losing a leg ... You’re not missing an arm or a leg. Everything is internally going wrong. It’s like you’ve been microwaved from the inside out.”

Paul uses a walking stick and, thus, his illness has been made visible. Whilst veterans would often discuss the missing limb as an image contrasted with their own,<sup>7</sup> I observed that the image most often associated with Gulf veterans was that of the once vibrant man now hobbling with a walking stick or in a wheelchair. Roughly 10 to 15 per cent of sufferers I met used one or two walking sticks and some reported that they sometimes found the need to use a wheelchair.

Many veterans described their frustration with the invisibility of their illness. Lee, an ill veteran who I met at the AGM explained,

Because I spoke earlier about how it’s really funny that you feel unwell but you can’t put your finger on it. You don’t know how tiring that can be, in the end. You want your head to hurt. You want your leg to drop off. You want some fucking evidence of it to ‘appen. Just so you can say ‘ah hah, so that’s what it is!’ ‘Cause after awhile it just really grinds you down. And there’s nothing you can do about it.

The suggestion is that an obvious, visible illness would be a relief. As a disputed and internal illness, GWS denies sufferers the identifiable mark they desire. They use walking sticks, point out visible marks on their body, wear badges and put stickers on their car to mark themselves as ill and as Gulf veterans.

As mentioned above, during the early days of my fieldwork I stayed in Leeds to observe a number of War Pension Tribunals. I arrived at my hotel and waited for Kerry to arrive. She soon walked into the lobby with a man with a walking stick who had a slow rolling gait – each step

7. A common perception is that children born to GW veterans are likely to be born missing limbs. It is as though the child embodies the war experience of the father, with the image of the war veteran as an amputee. In Chapter Six I will discuss the predominant role birth defects play in GWS narratives.

a struggle. She introduced me to her husband, a member of the GWVA. Whilst Kerry and he were checking in at the hotel reception he asked for a large pint of water, as he “needed to take a lot of pills”. Once he was given the water he proceeded to take 18 to 20 pills in the hotel reception. This was not to be the last time that a veteran took medication in front of me during one of our interviews.

As mentioned above, discussions of GWS inevitably become discussions about the testing of body substances. In an attempt to prove their illness veterans have undergone a plethora of testing and plan to undergo more testing in the future. Such a focus on testing can be seen as an attempt to make the invisible visible. Just as veterans sometime walk with walking sticks and wear badges marking them as a member of a Gulf veterans’ association, tests are tangible marks of identity as an ill Gulf veteran. However, veterans often express their frustration that tests most often come back as “negative”, pointing to the conclusion that there is nothing wrong with them. One veteran, Steve, suggested that coming to the AGM and meeting with other ill veterans allows him to “see” the illness. The community makes the illness visible:

Everything [tests] that comes back is OK, like so every time you are back to square one. What is it then? What’s all this that I could have caught there and this week I come here and I actually can see it with my own eyes ... I am expecting every result to come back bad, if you like ... like I’ve got something. I suppose for the past ten years I’ve just been expecting to die ... every time a result comes through. But as I say everything comes back clear. And that is why I’m glad I’ve come up here. It has opened my eyes ... Now that I have been here as a mark of respect to the people who have already died I think I will ... take part in the organization and be there as a body. To show my support [and] do more tests ... Everyone I seem to know, there is a negative attitude off them ... Um, because you look all right. There’s nothing the matter with you, like. They don’t seem to be a lot of support there.

Becoming part of the association also means, for Steve, to give his body for more testing. Participation and membership involve the body in a very direct way.

The desire to make the illness visible has developed into a desire for tests such as Magnetic Resonance Imaging (MRI) scans. One scientist is leading the way in such testing. Hayley, the Texan scientist funded by Ross Perot, is seen by veterans and their advocates as producing the most compelling evidence in support of GWS. By showing differences between “normal brains” and those of GWS sufferers on functional MRI and MRI spectroscopy, Haley’s work seem to make the affects of the illness visible. Body substances and parts of the body, veterans propose, will reveal the suffering they experience.



## Shifting Boundaries

Lee explained that in 1993 he began to feel unwell. He said that he had: “A general feeling, like when the word is on the top of your tongue but you can’t get it or can’t get an itch. I knew there was something wrong, but just couldn’t put my finger on it.” Lee explains that he felt like he wanted “to be stretched on a medieval rack” and he feels he was smaller, shorter than he used to be. Everyday, he said, he feels like he has been hit by a truck. Lee conceives of his body as a closed system with limited resources and sees the vaccines given to him as overloading his system. He could cope with a few:

But when you’ve got *multiple* ones whizzing all around your system the white blood aren’t Lynford Christie. There’s not enough of them to deal with all what’s in ya. You cannot keep putting a foreign substance into a sealed system without problems happening. It’s like hydraulics, it’s like a car. You can’t just keep filling up with petrol. It will only take so much ... any sealed system can only take so much and that’s the same with things like that. They overloaded the system that couldn’t cope.

Some veterans talk about their bodies actually changing form and shape – the boundaries have shifted. Two veterans think they have shrunk, and many say that they are bigger, fatter than they were. Other veterans suggest that they are smaller, thinner, that they have lost bulk and weight. Paul, introduced earlier, explains another affect of GWS on the body:

A lot of veterans have lung capacity problems and see specialists. Their lungs have physically shrunk because of GWS. And they’ve got that there as an accepted condition. [How would you describe your body?] I’ve collapsed. If you imagine a balloon being blown up: there’s air in it, it’s tight. It’s just collapsed. The air’s gone out of it: nothing there, there’s nothing inside.

Another veteran, Sean, explains that he feels like an “old man”, that he is “dying from the inside”. Tom says: “Everything we had – the NAPS, the vaccines – pick something up or been given something that’s slowly eating away at me. It’s dragging me down slowly. It’s like the immune system isn’t fighting off what it’s supposed to be and something inside me is stuck there.”

Veterans suggest that their bodies and their body boundaries have been altered by the exposures in the Gulf War. The body they used to know and its relationship to the world has changed. Veterans also commonly say that they bump into things and drop objects, as though they are unsure of their bodily place in the world. They are uncertain of their external boundaries as well as their internal barriers.

## Extended Boundaries

The perception of the shifting nature of body boundaries suggested by sufferers can be seen as part of a larger experiential system to which modern soldiers are exposed. In our contemporary era of nuclear and smart weapons the ability to destroy large numbers of bodies is matched by a partial pre-emptive disappearance of the body from representations of war (Gusterson 1991). The media representation of the Gulf War

[W]as remarkable for the way in which it treated bodies as objects for mechanical enhancement, weapons as surrogates for the bodies of warriors and, above all, for the extraordinary visual and thematic absence of dead, maimed, mutilated, strafed, charred, decapitated, pierced human bodies in a heavily televised war which surely claimed at least 100 000 casualties. (Gusterson 1991: 49)

Furthermore, supremacy in the Gulf War was often portrayed in terms of the allies' ability, through technology, to transcend the limitations of the human body and to re-engineer the human body. Whereas the Iraqis were constrained by their need to sleep and their inability to see in the dark,<sup>8</sup> the allies were enhancing their bodies and overcoming the limitations imposed upon them by their human bodies.

The vulnerability of "bodies to chemical and biological weapons was addressed with chemical protection suits and inoculations which supposedly armoured ordinarily fragile human bodies against such threats" (Gusterson 1991: 49). The bodies of allied warriors thus had a post-human, hybrid, cyborg-like quality which was emphasised by the media. Most images of the soldiers involved them wearing masks, full NBC suits, or night goggles, often obscuring their human qualities. Thus, bodies of soldiers had their boundaries extended and strengthened. Yet one wonders what happened to these soldiers' view of their bodies when these technological enhancements were stripped from them. By enhancing bodies, creating external barriers and strengthening internal ones, the measures enhanced the vulnerability, frailty and ineffectual nature of the human body. Similarly, the focus on technology results in an impoverishment of the human body and its boundaries.

8. Interestingly, in the recent conflict in the Gulf (2003) Donald Rumsfeld expressed extreme anger towards Syria because they were said to be smuggling night vision goggles to the Iraqi troops.

## Leaky Bodies

When Gulf veterans talk about their bodies they describe them as vulnerable, with barriers which are easily traversed. Body boundaries are porous, allowing dangerous outside elements to enter. In their discussions of their illness veterans often talk about substances which came out of their bodies. Martha told me of a woman she knows who was too ill to meet with me: her breasts “oozed green fluid”. A number of reported symptoms suggest an anxiety with one bodily substance being mixed with another. Bob, for example, said that he was concerned that he had found blood in his semen once and that he had found blood in his faeces.

As mentioned above, veterans often say that they “leak” and that they are unable to control their bowels. Many veterans report that they need to wear diapers because urine and faeces “leaked” out of their bodies. Orifices are discussed with anxiety. Women are thought to be at risk from catching GWS from their partners, with the mouth and vagina as the major entry points, as will be discussed in Chapter 6. Body orifices are also treated with anxiety with regard to the way they allowed exposures into the body. John described the risk of DU, particularly in terms of the way it entered the body through vulnerable points: “DU, my own belief is that mine was through breathing it in ... From the suspension in the air ... [it] got into my lungs and into blood stream and into my kidneys. I’ve got scarring to my left kidney ... which I never had prior to the Gulf.” Bodies are seen as vulnerable, particularly because they allow substances and toxins in. Bodies are permeable, allowing agents from the outside to pass into the body, but they are also porous and allow substances to leak out of the body.

### *Blood-brain Barrier*

One of the most discussed body barriers is an internal barrier implicated in one of the most commonly cited GWS theories of causation. The blood-brain barrier is an internal boundary protecting the brain from toxins carried in the blood. However, in Gulf veterans this barrier had been compromised, leading to many of the symptoms they report. In 1995 experimental evidence for a toxic synergy between Pyridostigmine bromide (PB), the active agent in NAPS, and insecticides in chickens was announced by Duke University researchers and published in the spring of 1996 (Wheelwright 2001). The main author, who focused on the synergistic effect of the Gulf exposures, had a theory, which was to

become popular with veterans and their advocates. Abou-Donia suggested that PB had somehow got into the brains of veterans:

[For it] to have caused injuries to vets' memories and concentration, the pyridostigmine must have passed from the bloodstreams of the subjects to their brains. The scientific understanding was that this drug normally could not cross the blood-brain barrier; however, at the end of 1996 an Israeli team, funded in part by the US Army, published an important paper suggesting the mechanism by which this may have occurred. (Wheelwright 2001: 385)

Friedman et al. (1996: 1382) described an experiment on mice that had been put under conditions of stress and when PB was injected, the drug affected their brains. Previous animal studies had shown stress-induced disruption of the blood-brain barrier and, so, the suggestion was put forward that the stress situation associated with war allowed pyridostigmine penetration into the brain. The study claimed to have found that the "blood-brain barrier had breaches and leaks that could have resulted in chemicals and bacteria and viruses penetrating the brain and chemicals in the brain leaking into the bloodstream". This study suggested that PB affected that central nervous system of Gulf veterans and caused symptoms such as memory and concentration problems. Hence, the idea that PB traverses the blood-brain barrier by way of stress gained popularity.

In October 1999 a Defence Department consultant made news with the publication of a scientific review of PB. Her conclusion was that the use of the drug by 250,000 soldiers "cannot be ruled out" as a source of the nagging illnesses. "Stressful or other special conditions may allow PB to breach the blood-brain barrier and penetrate the brain, producing effects that would not 'normally' occur" (Golomb 1999 in Wheelwright 2001: 386). Six months later, however, the scientific opinion began to shift when the Israeli findings on PB's penetration of the brain were not duplicated by others (Wheelwright 2001; see Grauer et al. 2000). Veterans and their advocates, however, remain convinced of the blood-brain permeability hypothesis.

Hooper is confident of the permeability theory and often speaks of the compromised blood-brain barrier, veterans' leaky guts and gut permeability. This view of veterans as having compromised body boundaries pervades his work. At the London US Congressional meeting in 2003 Hooper discussed Goran Jamal's work, which suggests that GWS involves damage to the nervous system. He argues that the nervous system is a sensitive organ to assault, especially by toxins. Furthermore, he puts forward that "the whole system was protected by

a shield: the blood-brain barrier". Although this barrier is normally closed, something in the Gulf War, he suggests, opened the barrier and let in toxins. Hooper adds to the theory by connecting the blood-brain barrier to that of other membrane barriers which line "the gut and the lungs", barriers which "prevent many compounds from crossing these membranes" (Hooper 2003: 1). However, some chemicals, he suggests, are known to "open these tight cell junctions, allowing free transport into the previously protected areas of what ought to be excluded compounds". Hooper stated: "The compromised gut wall is 'leaky' and allows the opioid peptides resulting in extensive modulation of peripheral and central opioid effects. The central effects include changes in behaviour, cognition, perception and mood via major effects on the higher executive functions" (2000: 6).

When the gut wall has increased permeability, the "opioid peptides (casomorphin and gliadomorphin) which would normally be excluded are absorbed into the blood stream, giving rise to diffuse symptomatology and systemic dysfunction" (Hooper 2003). Hooper links this to the inflammation of the gut which, he cites, is common among ME patients and GWS sufferers, as are allergic reactions to foods containing gluten. The "compromised gut facilitates the development of a gut dysbiosis which in turn can give rise to autoimmune diseases, with very significant and chronic damage to health" (Hooper 2003: 1). Thus, Hooper further emphasises the permeable nature of other body barriers, particularly the gut. In so doing, Hooper describes the bodies of Gulf veterans as leaky and vulnerable.

As mentioned previously, Hooper recommends the IAg test, since in "other chemically poisoned people; in nearly every case, high levels of IAg appeared in their urine" (ibid.). He continues to suggest that, "For this to be happening means a dysfunctional gut and sufferers from these overlapping conditions show evidence of a 'leaky gut', i.e. an increased permeability of the gut wall due to damaged membranes. Hooper explains that this happens in people who are described by certain psychiatrists as exhibiting 'MUPS' ('multiple unexplained physical symptoms')" (ibid.). He suggested that their

[M]ultitude of symptoms are not "unexplained" at all and that they are entirely organic in origin ... In summary, the IAg system involves the gut, brain, endocrine and immune systems: in ME, it is clear that the biochemical deficits are extensive. Detoxification is essential. Hooper sets out the basis for the neurological damage produced by a common mechanism but by different insults, biological or chemical, producing symptoms common to these overlapping syndromes, including ME. (Hooper 2003: 1)

Thus, Hooper connects the gut function to other parts of the body, including the immune system. He recommends that Gulf veterans maintain a non-dairy, non-gluten diet because food contains toxins and allows these toxins to pass into the body. Hooper is also concerned about additives, sweeteners, colouring agents and “other ingredients in ‘junk’ foods”, as well as pesticides and preservatives “routinely consumed in food” (2000: 13). Many veterans have taken his advice and altered their diets, focusing on flushing “toxins” out of the body and minimising their entry into the body.

Ann, the veteran introduced in the previous chapter, joined the army in 1975 and trained as a nurse. She took voluntary redundancy in 1993 as part of “Options for Change”. In 1997<sup>9</sup> she began to notice a number of symptoms including blurred vision, dimmed vision, muscular problems, excessive sweating and increased irritability. Her personality started to change and she had dental problems, stomach and gastric problems and she was later diagnosed with Irritable Bowel Syndrome. She said her main symptoms at present are fatigue, sweating, temper, and irritability and when I met her she used a walking stick to support herself. When I asked Ann if she did anything special for the sake of her health she responded:

I didn't actually tell you about, you've heard them talk about Paul Shattock? IAg, whatever, that test that they talk about? Well, I've had that test done and I've actually got that. I know it is an experimental test. But it goes on this permeability thing, doesn't it. If you've got gut permeability, so you are going to have brain permeability. So if you eat gluten ... then it gets through and it causes all these cognitive [problems] ... And I think, again that the vaccines have caused this kind of, or even the organophosphates.

Bodies of GWS sufferers are understood by them and their advocates to be leaky and porous. Inner barriers that are understood to protect the parts of the body from contamination by each other or by toxins are permeable, allowing substances to flow freely between them. Food is problematic as it crosses body boundaries, but it is also seen as potentially dangerous as a carrier of toxins that traverse already weakened barriers.

9. Although Ann said her symptoms began in 1997 she said that now that she looks back she can link other problems which started in 1993 to GWS.

## Internal Risks

Veterans see their bodies as perennially at risk. Risks are ever-present in the form of toxins and chemicals in the outside environment, yet one's internal environment is also a source of risk. Illnesses lie dormant in the body, waiting to be triggered, as will be discussed in the next chapter. As mentioned in Chapter 1, veterans see themselves as ill as a result of exposure to toxins in the Gulf War. They perceive the war to have been a uniquely toxic environment. However, the world in which they live remains toxic and full of risk. Many veterans remain concerned about the amount of toxins and chemicals present in their environment and suggest that they are more sensitive to such poisons as a result of Gulf exposures. William emphasises his concern with past and present exposures:

I have now heard that as well as the inoculations, some of these things had additives put in. Now, I don't know what they were, but I do know that any chemicals in this day and age can damage body parts. Heavy metals have always been known to be very damaging. I don't know how they work, but they do damage the body. Radioactive things damage the body. I believe that many chemicals in everyday use can damage the body. I feel that by pumping things into your body and your blood stream can have a very detrimental effect. I'm not qualified to say how, but I have a belief that they do.

William also suggests that he is concerned about a number of issues, including chemicals in the environment. He explains that he used not to be worried about such things, but now he feels he is more susceptible to them.

I'm now using solvents at work I always try to put a mask on and wear gloves so I don't come in contact with chemicals. I try to avoid foods that I know have a lot of additives. I always wash vegetables and fruits before eating them because I believe they spray them with chemicals which I don't want to take. I rarely eat chicken because I believe that they are kept in terrible conditions and inoculated. I try to avoid eating very much meat. I believe most of our meat is filled up with inoculations and growth hormones. I nearly always buy organic things in the shops ... We use too many plastics: they are in our environment. I do believe chemicals do build up. I always have windows open. I feel there are a lot of chemicals and modern substances that giving off vapours the whole time that are very bad and I think they will be proved in the future to be very harmful to people's health.

William explains that he has only been taking such precautions in the past ten years or since he had become ill. He is unsure what had started these concerns, but wonders whether it is because these issues had only recently received press coverage. However, he also said that, "At one stage of my illnesses I felt I had been poisoned. I felt so wretched. Every part of my body felt awful, like I had been poisoned". William also suggests that he feels there is more aggression and anger in the world because things were not as simple as they used to be. He links poison and toxicity to the state of the world and society.

Many veterans also complain of Multiple Chemical Sensitivity or more general sensitivity to environmental toxins. Ann explains, "I have increased chemical sensitivity. [I] can't wear perfume, had to change deodorant. Rash ... my skin splits, itching".

Veterans commonly explain that they are more sensitive as a result of their experiences in the Gulf. This sensitivity is entirely linked with a distinction between natural substances and man-made/toxic substances. There is a suggestion that the bodies of veterans react adversely to anything unnatural. As Donald said,

We are going against nature. In the Gulf too we messed around with things. Sometimes get away with it. Sometimes you don't. Why expose children to pylons? Hotspots are about people with leukaemia living near pylons. Still they say no. But tell that to those with leukaemia. Those autistic children with MMR. For all our years we had three vaccines: it's all financially driven so why we do these things? Win some and lose some. Can't all be bad and harmful and not none bad and harmful. They tell you not to have too many x rays.

When I asked Paul if he is concerned about GM foods he suggests that he is concerned, yet he also made a link between GM foods, another war and its toxic exposure.

Monsanto. That goes as far back as Agent Orange and Vietnam. Still people dying in Vietnam of leukaemia through Agent Orange. I try not to eat GM foods. It's man made. [Do you eat only organic food?] No I don't eat that, but I try not to eat GM foods. [Are you concerned about chemical sensitivity?] Yes. I get that. I'm more sensitive now to cleaning stuff like bleach. Petrol fumes, as well, bring me back to the Basra Road. Especially burnt [smells remind me of] petrol bombs. Like when kids get a car and burn it out. It never effected me before, but it effects me now ... more sensitive to it now. [Do you have any concerns about mobile phones?] I have a mobile phone and I keep it in my pocket. Not in my inner pocket, in my jacket pocket, but once I'm in the house I'll leave it in the corridor.



Whereas the environment and the toxins contained in it are uncontrollable, as mentioned above, many veterans have altered their diets in response to their illness. Able to control what they put *into* their bodies, veterans commonly restrict their diets, a suggestion advocated by Hooper. Ed's diet is illustrative of the kind of Gulf veterans' altered attitude to food:

My diet, I've become sensitive to gluten products. Milk, I can't have milk. I have to have a different butter. A vegetarian butter. A gluten-free butter. Umm cheese, I can't touch cheese. Alcohol, I have to drink in moderation. Umm, what else is there? I can only have plain crisps. Because of the flavours ... e numbers. Chinese food I can't eat because I'm on the sodium glutamate, spicy food. Anything, basically I have to check e numbers to see what's in it. Ummm it can be a pain. You spend double the time when you go shopping for food checking what's actually in there.

As in the previous chapter, we can see here how veterans encompass theories from the world around them. Food sensitivities and allergies have been increasingly focused upon and are often tied into notions of identity. Veterans such as Ed say that because of their illness they are more sensitive to certain foods and products. Many veterans maintain the gluten-free, dairy-free diet recommended by Hooper in an attempt to reduce complications of the "leaky gut", discussed above. Much of this sensitivity is linked to artificiality and what they see as toxins. Dietary restrictions most often stem from an attempt to limit the amount of toxins entering the body. Ann describes how she has created a regimen focused on "de-toxing the body":

Yes, I've got the diet and I've started taking multivitamin tablets. I'm also on MSN, which I think we talked a little bit about. [What's that?]

It's the sulphur, the organic sulphur type stuff. I also take flax seed oils, which has got Omega 369. I take one of them daily. I also have Epsom Salts to have a bath. It helps you sweat out and it also helps you to absorb in. See, magnesium's a problem and that's what it is, Epsom Salts magnesium. Umm, so that's what I do. I filter my water now, what I drink. I, ah, I mean, my diet has changed quite radically because of what I'm eating now ... Yes. I feel that at some levels, the food, you are what you eat and I believe that. Our engine can't work without petrol.

Veterans like Ann are concerned about putting the correct (non-toxic) things into the body and leeching out the toxins from inside their body. John explains that he does a number of things to improve his health. All of these things are intended to extract toxins from the body. He says that he takes vitamin C daily in order to boost his immune system and

because its “got an anti-toxins in it.” Thus, it is “common sense to try it”. John also takes “Maximul, which is a multi-mineral drink” and continued that it was important to “understand the basis of body function and keep those basics up and running”. All of these things, he says, “help to remove the toxins”. He continues to describe the things he did to reduce toxins:

And to increase the water you drink as well. Water intake to flush as much of the crap away as you can. I do saunas as well. Which again is the advice that my neurologist said – “John, take as many saunas as you can”. And he referred to arsenic. He said arsenic, for instance, can take many, many years to come out of the body. And, of course, arsenic was one of the chemical compounds that we were exposed to. Either from the oil fields or from the munitions that were fired.

A common belief is that the body conceals illness inside itself. Illness is always present but lies dormant, waiting to be activated by some external agent: a trigger. It is as though individuals are always ill or are in a constant state of potential illness. Triggers are diverse, but often chemicals and other dangerous agents are identified. One veteran, Sara, explains her understanding of cancer:

I think it is something that lies dormant in your body. I think everyone has it and it takes something to trigger it ... It could be chemical related. Maybe using a certain type of washing powder ... All of a sudden one day you visit somewhere and it triggers it. Something that is dormant and something triggers it. I don't know what the trigger would be, whether it's chemical or something. I probably think it would be chemical. Some kind of manufactured drug, or bleach, or disinfectant, or something that's sprayed on crops. Just something that triggers it, but I think everyone's got it. And not everyone's found their particular trigger. Not everyone would have the same trigger. Just something that kicks it off.

The notion of dormant illness will be discussed in the next chapter, but it is important to note in this chapter on body boundaries that internal threats are also present.

## **Conclusions**

The body is one of the places in which social concerns are symbolically enacted (Douglas 1966). Douglas showed that the human body serves as a mirror for society, with powers and dangers credited to the social structure writ upon the body. The “body is a model which can stand for

any bounded system. Its boundaries can represent any boundaries which are threatened and precarious. The body is a complex structure. The functions of its different parts and their relation afford a source of symbols for other complex structures" (1966: 115).

Douglas has shown that threats to society are reproduced symbolically in conceptions of the human body: "we should expect the orifices of the body to symbolise its specially vulnerable points" (1966: 121). The fluids of the body turn out to be a kind of language in which various themes find their voice. Bodily margins are thought to be specially invested with power and danger and "[m]atter issuing from them is marginal stuff of the most obvious kind. Spittle, blood, milk, urine, faeces or tears by simply issuing forth have traversed the boundary of the body" (*ibid.*). Furthermore, Douglas asserts that an anxiety about orifices suggests a corresponding sociological desire to protect the political and cultural unity of the group.

People employ notions of barriers and boundaries as well as their permeation by bodily fluids when thinking through issues of health and illness (Claeson et al. 1996). In their interviews Claeson et al. (1996) found that talk of vulnerability of bodily boundaries shifted easily from the level of the body to wider social issues such as neighbourhoods and nations. Boundaries have a social significance. They mark off or contain areas of safety outside of which dangers lurk. Moreover, if one knowingly crosses such barriers one might be opening oneself to harm. Similarly, the words veterans use to describe the world of the body also orient their understanding of social interaction and politics (Claeson et al. 1996).

Militaries emphasise certain boundaries such as that between men and women, soldiers and civilians, the fit and the unfit. Through a variety of practices soldiers are held up as different from civilians: they wear uniforms, they abide by certain rules. Militaries create strong borders which separate them from the rest of society, but internal margins are also important, such as those between different ranks and different occupations. The military, however, could also be seen as a boundary-busting institution. Boundaries which are normally accepted are not present in the military. Military practices such as men living, showering and bonding with other men are one example of the way expected boundaries shift in military culture. The ability to kill is another way that cultural boundaries are altered in military culture. Body boundaries are extended as the military, or the unit, is taught to be seen as one large body. Yet in the lives of the soldiers I interviewed, the military was also border-breaking in that the military itself invaded their bodies. Through injections and pills the body was entered and

altered. The body was extended and their outer borders altered through a variety of measures: NBC suits, night goggles, masks.

In Chapter 7 the notion of shifting boundaries in the military culture of the past decade will be discussed. I suggest that the soldiers' notions of permeable barriers and vulnerable body boundaries are a reflection of their specific experiences. Their body boundaries are no longer protective and definite in the same way that military boundaries are no longer structured and isolating. The body is symbolically enacting social experiences and concerns. The main concerns about bodily substances are of its contagious nature (sweat, semen), with the substances as material to be interpreted (urine, blood), and with the substance as a way of flushing the body (faeces, urine, sweat). Body boundaries are seen as fluid, permeable and vulnerable – unable to protect one from the ever-present threat of toxic risk. As will be discussed in depth in Chapter 7, there are a high proportion of sufferers who had supportive roles: as chefs, medical technicians, nurses. It is important to note that these jobs involve bodily substances and traversing bodily boundaries.

## Chapter 4

### **“WE ARE THE ENEMY”**

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We have seen in the preceding chapters that veterans experience the world as full of risk and danger, particularly with regard to the toxins they were exposed to in the Gulf War. Veterans show a great concern for body boundaries and the permeability of these frontiers. Just as there is an anxiety about body frontiers, so too is there an anxiety about inner boundaries. In this section I will extend the notion of boundaries and look within the body at that component which is seen as the consummate barrier to threat and illness: the immune system. My interviews with Gulf veterans were dominated by their focus on the immune system and its role in GWS theories. GWS sufferers almost universally see their illness as being caused by a weakened immune system which is seen as the result of the vaccinations and other exposures. Situating the illness in discussions of the immune system provides a biomedical and inclusive model for their suffering.

That GWS is due to an immune system reaction or failure was established very early on: this idea was mentioned in more than a quarter of newspaper articles in the first two years of reporting. In a newspaper review of a Channel Four programme, a soldier is described whose “immune system has vanished. He lives in a room lagged with tin foil against the risk of infection with a blue plastic tube inserted into his nostrils” (Norman 1993). Others make a complicated link between allergies, the immune system and microbiology, such as in the following quotation from a *Today* article on 23 June 1993, “those who simply became allergic to the cocktail [of NAPS/immunizations] ... will have to wait months, perhaps years, before their immune system recovers. They will get every virus going.”

In the early parts of the twentieth century, the most important threats to health were considered to lie outside the body (Martin 1993). The body boundaries themselves were seen as the main defence and the focus was on preventing the entrance of germs into the body (Clark and Cumley 1953: 103). Martin (1993) reveals that attention to the threats which lie in the environment outside the body shifts to an emphasis on the defences within the body. As Shorter explains, since the “1960s immunology has become the queen bee of the medical sciences, in the way that pathology was in the nineteenth century the foundation of all further knowledge” (1992: 314). The concept of the immune system under assault and giving way under pressures of twentieth-century life is a key idea in understanding illness beliefs at the end of the twentieth century (Shorter 1992; Wessely 1997). This concern with the immune system can also be seen to draw on the fears of another late twentieth century disease affecting the immune system: AIDS. Explicit links were made in media reports between GWS and AIDS, central to this connection being the involvement of the immune system. We can see the way GWS was being talked about and framed was influenced by popular understandings of illness.

## **Boundaries and Borders**

In my interviews there was widespread agreement that the immune system was something contained within our bodies that protects us from disease. Borders and boundaries permeate talk of the immune system, which is seen as a barrier to illness. For most people, it is this system which determines whether one is going to get ill or remain well. Such findings reflect Martin’s work. As she states, it “seems to follow from a robust notion of an internal system of protection that the system exists to ward off continual threats. People focus their attention on the well-being of the system rather than on creating an environment that is free from threat” (1994: 67). In my interviews, people frequently express the notion that the environment surrounding our bodies contains many dangers that cannot be eliminated. Staying healthy is primarily about maintaining a strong immune system, but for sufferers of GWS, their immune systems are damaged and, thus, this defensive boundary is compromised. They are left vulnerable.

The immune system took centre stage right at the beginning of my fieldwork. My very first contact with veterans was when I made a phone call to Ken, the head of one of the veterans’ associations. As we began speaking about GWS he said to me: “it’s all down to damage to the immune system because of vaccines. Like a house that has been

damaged, it will fall down." We can see that the immune system is perceived in terms of barriers that are strong and solid when well, keeping the person free from disease. However, when they are permeable and fragile, like those of Gulf veterans, they will allow the whole system to collapse. Harry suggests that the immune system is a:

Barrier towards disease, really like. I'm not saying it's a 100 per cent barrier toward disease, but I think if it's affected in any way you have more chance of becoming ill ... I think everybody's different. A lot of us are getting a lot of the same conditions coming through but at the same time some people are getting different conditions, I don't know, I think everyone is an individual.

Harry sees the immune system as a barrier, but one that even in healthy people is not completely infallible. This would explain why all people, even those with healthy immune systems, are vulnerable to disease. Harry emphasises the individual nature of the immune system and of the illness itself.

The protective effectiveness of Gulf veterans' immune systems differs from healthy individuals. When I asked Ed, the veteran discussed in the previous chapter, what the difference is between him and a healthy person, he responded:

Well, I mean, they are strong all the time, they are able to do physical exercise. Ummm, you know, where I would fall after like, well ... I can't run ... I get out of breath after five minutes, where a stronger person with a stronger immune system would be able to cope better than I would ... Well, they've got a solid wall there. They have got whatever in reserve to help them, back them up. They're more fitter and healthier ... But they have got a good solid defence there. And it can recognise the symptoms early to fight them. The brain knows, the body knows, "there's an infection coming here, let's fight it". Where ours is a lot slower or non-existent.

As Ed suggests, a healthy person has a strong perimeter that is able to resist threat. As a GWS sufferer, Ed imagines that his immune system is permeable and does not provide a solid defence, which makes him less able to cope with surrounding illnesses. A strong body is equated with a strong immune system. Ed also imagines that his immune system, along with other sufferers, is sluggish and unable to "recognise" illness effectively. Martin's (1993) history of the immune system shows that the interior lines of defence of the body are further elaborated in time. "Recognition' is fantastically honed and refined and the immune system 'tailors' highly specific responses that can be almost unimaginably various. Drawing on an immense genetically generated and constantly

changing arsenal of resources, the body can hardly rely on habit any longer" (1993: 72). The immune system is agile, constantly learning, remembering and responding to the world. In immunology the emphasis is on flexibility and adaptability (Martin 1994), but veterans suggest that their body was in the end unable to respond to the sheer demands of flexibility upon it.

Recognition is key to understanding the immune system. This subject will be explored in depth below. However, it is important to note that veterans understand vaccines as introducing information into the body so that the body is able to "remember" and provide protection when faced with the real threat. Veterans suggest that vaccines prompt the immune system to produce a barrier to that specific threat. Jeremy, a healthy Gulf veteran, suggests that a vaccine is a: "Prevention. The solution goes into your blood stream to help fight with the immune system. Helps to fight alongside your own immune system. If you do get the germ, the bug, you do have a barrier. Injection is a barrier." The immune system is a general protection, but can develop specific barriers through inoculation. Veterans, however, suggest that the body was overloaded and unable to respond to each specific education/vaccination in the Gulf, resulting in a breakdown of the general wall of defence.

GWS sufferers understand their illnesses as arising out of this weakened immune system. Their immune system is "down" and, thus, they are left defenceless and open to peril. They are vulnerable to the perpetual threat of infection and illness. Veterans say they continually suffer from colds, flu and coughs – the most common forms of illness. They suggest that unlike healthy people, they do not have a strong border to hold off germs and viruses which are present in the outside environment. As Ben says, "I was never susceptible to cold and flu before, but now I catch everything around. It's like everything, any germ that's around, 'come and get me!' I am a perfect host for them. Most of my medical history has been since 1991."

A common theme of veterans' narratives is that not only are they more vulnerable to illness, but when illness appears it takes over more completely and for a longer period. Whilst for "normal" people, germs and bugs are held at bay and only take hold rarely and briefly, GWS sufferers have no such defence. Another aspect of this inactive immune system, veterans explain, is that cuts and other skin conditions do not heal as they are supposed to. It is as though the skin, the body's visible meeting point with the outside environment is not coping with the encounter. Veterans constantly compare themselves and their systems to "normal" and healthy people, against whose theirs are inadequate. When I asked Paul what he imagines happening inside a healthy person's body when they get a cold he said:



I think the immune system will fight it, obviously. Or put up antibodies; is it antibodies? The cells fight. The white blood cells fight with the red, or something. Something is carried in the cells. [How this differs when a Gulf veteran gets a cold?] I think they haven't got the immune system to fight it off. That's the bottom line. Their health is collapsing. Some get colds for months.

A concern with the immune system and the permeability of body boundaries can be seen to draw on the fears of another late twentieth-century disease affecting the immune system: AIDS. Links are often made in the media and amongst veterans between GWS and AIDS. One early media report said of GWS: "It's like AIDS. It's not the AIDS that kills you, it is the collapse of the immune system" (Walker 1994). A number of veterans I spoke to make a connection between GWS and AIDS. Richard, a healthy Gulf veteran, said that people with GWS "look not dissimilar to those dying of AIDS". He suggests that they looked weak and emaciated and that their immune systems have turned on them. When I asked another veteran, Mick, what he felt was the illness most similar to GWS, he said, "To GWS? AIDS, I suppose would be the nearest thing to it. The way, how it effects your immune system. It eats away at it. These people look as though they've aged 40 odd years in the matter of a year."

In some cases the link between GWS and AIDS is made more direct and more sinister. A veteran, who I later met, was featured in a story in *The X Factor*, a magazine about "cover-ups, paranormal, mysteries and UFOs". The article discusses how one veteran claims that cytokines were injected into troops to defend against Nuclear, Biological and Chemical (NBC) attack, but there was not enough to go around. Consequently, he claims, "it was decided to include a second, untested component that duplicated the effect of the cytokines". The article continues to say "Parker claims that this second component was HIV genes ... the consequences of injecting HIV genes – which allegedly cause the AIDS virus – are not known. The worst possible scenario, some claim, is that allied troops may have been infected with the condition that allows for the development of AIDS" (1997: 542).

## **Theories of Causation and the Immune System**

The immune system is central to the theories of causation of GWS, including severity of illness and infection rates. The illness involves a depleted immune system; the various specific illnesses and symptoms arise out of this deficiency. The immune system theory enables

veterans to make a coherent, inclusive system out of the incoherent. It provides explanations to a number of anomalies that are indicated by their critics, such as why it is that the majority of veterans remain unaffected.<sup>1</sup> When asked why they think some got ill and others did not, most veterans suggest that this was due to the pre-war strength of an individual's immune system.<sup>2</sup> As Cameron, an ill veteran, discusses, "It could be their immune system, in the first place, were a lot stronger than the guys that have developed the illness. The general health I think before they went out there. Not the state of mind, but a weaker physical, the immune system, things are going to attack you more."

Similarly, those who remain healthy make sense of their avoidance of illness in terms of their immune system. Healthy veterans say they either do not believe that there is such a thing as GWS or suggest that they were somehow different from those that became ill. The immune system is central to this difference. James, a healthy Gulf veteran says, "Maybe I had a tough immune system. I was tough and healthy, so it protected me." Again, immune system potency and bodily strength are synonymous.

This model also responds to another question upon which non-believers focus. Critics of GWS often point to the fact that the illness emerged many years after the end of the war, as evidence of the absence of a unique disease entity. Indeed, veterans are still coming forward. The theory that the immune system naturally degrades with age allows veterans an illness model which responds to such criticism and scepticism. This theory of the illness provides an explanation for why it is that the illness took years to emerge and continues to appear to this day. Furthermore, this theory follows on logically from discussions above, which establish that young veterans were more protected by their immune systems. The following discussion took place within a focus group of leaders and members of the association. Jack says,

In the past people have turned around to John and said, "OK, if there is a GWS why weren't all vets ill three years after the war. Why are more and more people coming forward?" So people ask John if GWS exists why are

1. It is important to note, however, that sufferers and their advocates commonly suggest that the majority of veterans are ill. They suggest that many will not come forward for fear of what might happen to them. I have also been told on many occasions that most veterans are ill, they simply do not admit it or recognise it in themselves.
2. Levels of exposure and/or location also play a role in theories of causation, as discussed in Chapter 1.

there not more coming forward? Gulf War illness affects the immune system. When we went to the Gulf we were young and our immune systems were immaculate. Obviously the older we get our immune system gets slightly weaker. So therefore all these illnesses and all these various things that we have been subjected to, whether its been NAPS tablets, whether it be oil well fires, whether it be depleted uranium, whether it be injections, all these things then as we get older our bodies then can't fight so that is why more and more people are becoming ill.

John adds to Jack's comments:

There is clearly a body burden on the troops. For some people it's greater than others. And I believe ... the younger ones at the time of the Gulf War when they came back didn't become as ill as the older ones. I know that's quite obvious to some people. You did have many, a lot of reservists at the age of 40 or 50 at the time of the Gulf War who became ill very quickly after the Gulf War. The next in line you have those who at the time were 30 years old, like myself, who became ill [in the] '93-'96 time period. And then after that the younger ones as they get older their immune system are breaking down because of the body burden that they are carrying because of the vaccines, the DU, or the chemical compounds that they've been exposed to, we don't know. I personally believe that the vaccines and medication we were given were the first insult to the immune system and anything else after that was secondary. And whether those people that were insulted at the time their immune system didn't recover in time to react against the organophosphate compounds that were in the air. Or indeed, DU. Maybe the younger people, their immune system did recover to give them protection. Maybe for younger people their immune system was strong enough to bounce back and protect them ... But, ah, it certainly seems to be a burden on the immune system that seems to have caused the problems. All our illnesses are auto-immune-type related or they seem to be.

Immune systems are understood by veterans to degrade naturally with age, but the above quotations reveal that there is a more complicated relationship between illness, exposures, immune systems and age. John suggests that young soldiers' stronger immune systems may have been able to respond more quickly to the initial "insult"<sup>3</sup> of vaccinations and were thus prepared for the next set of exposures. Young soldiers' immune systems are more robust and are able to respond more quickly to the outside world, he explains. This resonates with Martin's (1994) suggestion that effectiveness of immune systems

3. Insult is an interesting choice of word as it invokes notions of offence, indignity and assault, but is also commonly used in biomedical discourses.

was based on the notion of flexibility and an ability to adapt to novel stimuli. Veterans suggest that the vaccines and other exposures somehow remain in one's body. The immune system if strong and young is able to hold it at bay, but once the immune system degrades the burden is too much and illnesses take hold. The body is in a constant reactive state, responding to the exposures contained in the body and the outside world. However, Jack suggests that there comes a point where the immune system degrades too much and the illness succeeds in taking control.

In some cases specific individuals were used to illustrate this age-related theory. Major Ian Hill<sup>4</sup> was a Gulf War veteran who died at the age of 54 "of GWS"<sup>5</sup> in March 2001. Very much in the public eye, Hill was a leading GWS campaigner and the founding member and chairman of the veterans' association. He is compared to the present chairman of the association, who took over the public face of the illness following Hill's decline. The present chairman is younger, and, thus, his illness appeared later. Although the importance of age in the onset of the illness was often cited, I found that the veterans did not strictly adhere to their own theory. There were many exceptions and informants would often contradict this theory in the same interview. One thing struck me over and over again as I was studying GWS: there seemed to be no laws, no patterns nor rules to the illness. Veterans are clearly trying to make sense of the chaos of the illness by creating patterns, regardless of whether or not they strictly believe or adhere to them.

Immune systems are not created equal. Some people's immune systems were able to cope with the vaccinations in the Gulf, and thus, were not later affected. The immune system is also seen as highly individualised, with different factors affecting its strength and ability to protect. Age and physical fitness are regarded as central to this understanding: older veterans are more susceptible to the exposures because their immune systems are innately weaker. This does not mean, however, that those who were young and fit are exempt. Instead, a linear model of the illness is presented. Older veterans are seen as more vulnerable and, thus, succumbed first to the illness. As Debbie, who was introduced in Chapter 1, stated:

If you look really closely to it, it's the age of them. The younger ones are slightly fitter at the moment. But as time goes on they're not. And really ill

4. Major Ian Hill was a Royal Army Medical Corps theatre nurse reservist. He was flown home after reacting badly to the cocktail of vaccines given to soldiers.
5. On his death certificate his death is reported as due to a blood clot, I was told by a variety of scientists.

ones that I've seen are quite a bit older than Mark. They've been in their 40s and that ... I think a lot of it is to do with your fitness. As soon as Mark stopped work he had problems ... as soon as he stopped work he got problems straight away. I think it gets you when you are at home ... And the ones that were in from the TA [Territorial Army] they weren't as fit as regular soldiers. All the TA are coming off the street, at the end of the day. I think that has a lot to do with it as well.

Thus, the threat is ever present. Nobody is safe from the illness in this theory, as those that were young and strong and remain disease free at present are still at risk. As we can see from these comments such discussions of the immune system are part of the way they see the social world. Such discussions often reflect a person's wider social beliefs. Debbie establishes here that she has a system of hierarchy where Territorial Army<sup>6</sup> and old soldiers are weaker and more susceptible to illness. Debbie later expanded on this and made it very clear that she had disdain for TA soldiers and saw them as inferior to regular soldiers like herself and her husband. In her mind, this is linked to their inferior immune systems. Debbie also places unemployment into her theory of the illness. The words people use to describe the world of the body also orient their understanding of social interaction and their overarching views of the world (Claeson et al. 1996).

At times the onset of illness, with its link to a degraded immune system, is associated with the social experience of leaving the forces. There is a sense that the lifestyle in the army with its focus on physical strength and health kept the inevitable threat of illness at bay. As George suggests:

Guys that were just leaving the service, because obviously when you are in the service you are really fit and then within a couple of years of them coming out, the symptoms all kicked in because their fitness level dropped ... Obviously, again, it must be, there must be a connection between the immune system and physical fitness. Once your fitness level drops off a bit, all this kicks in. I think with Chronic Fatigue, with athletics you see even in civilian life – once they stop their training as such, then some of those have become ill. Some yachtswoman, I can't remember her name now, but within a year of her finishing her around the world trip or something, she got Chronic Fatigue.

6. The Territorial Army is a part-time volunteer reserve force. These soldiers often have other careers and are required to commit to 30 days: usually one evening a week, one weekend a month and two weeks a year.

I would suggest that this reflects the veteran's experience of their life unravelling when they left the service. Whilst they remained in the forces their lives and bodies were organised and contained by the military – their immune system in control – but once they leave the structure of their military life their bodies rebel. This theory of the illness reflects scientific finding which suggests that those who left the forces are more likely to develop the illness.

Martin suggests that we are seeing the creation of new norms which are based on a healthy immune system, in which some individuals have healthier ones than others (1993: 71); certain categories of people are found wanting (Martin 1993). Martin suggests these categories would most likely be women and people of colour, but in my largely male and white informant group, I found that it was the old and unfit whose bodies failed when challenged. Indeed, I suggest that the ideas contained in their narratives reflect their views that as they age, unfit men who have left the military and ultimately the work force, like their immune system, do not fit the norm.

Veterans expand on the individuality of immune systems by employing genetic theories: one's immune system's "natural" strength is determined by genetic factors. When asked why some veterans of the Gulf War were able to remain healthy, one healthy veteran, Nigel, responded:

Genes affecting the immune system. Why did some people survive the Black Death and some didn't? It's a lottery, isn't it? There was a programme recently about the Black Death and they looked at genetics in one village. So yeah, I think some people's immune systems are more vulnerable than others.<sup>7</sup>

By placing their understanding of their illness in discussions of genetics and the immune system, they are using the most potent medical language available. By focusing on the genetic element of immune systems, veterans also seem to suggest that there is little one can do to take control of one's health. They believe one must be healthy to stay healthy and suggest that once the immune system is damaged nothing can be done. The following quotation by Frank is a typical response to the question, "is there anything you can do to boost your immune system?"

7. Interestingly, a number of people used this television programme in their explanations of immune systems and genetics.

Um, keeping healthy? But you need to be healthy to start with to be healthy. When I was a PTI<sup>8</sup> rarely did I get coughs or colds. I was outside all the time. Anything wooshed through my body that fast came out again. I don't know if you can actually improve your health. I think you could, but you would have to be healthy to start with.

Although some spoke about things they did to boost their immune system, they were the exception. The majority of my informants responded negatively when I asked them if they did anything to keep themselves healthy or to boost their immune system. Many said that the best way to boost one's immune system was to be physically fit, but as they were so ill this was impossible for them. The veterans that said that they did do things to boost their immune system focused mainly on diet (vitamins, gluten-free food) and keeping the level of toxins they were exposed to, to a minimum. Interestingly, the one person who focused on boosting his immune system (and had changed his entire lifestyle to do so) was one of only three people who were ill but did not associate their illness with the Gulf. It appears that to have GWS means having an irrevocably damaged immune system.

### *On Standby*

In addition to constant colds and flu, veterans also suffer from more serious ailments, which are also explained by way of the immune system. All illness is due to immune system failure and, thus, all of their conditions can be linked to GWS by way of its effect on the immune system. Lee is a GWS sufferer who is awaiting a diagnosis of Multiple Sclerosis (MS). I asked him if he thought his MS was linked to GWS.

Yeah, undoubtedly. Because MS only happens when your auto-immune system has been damaged. This much I've read from all the MS literature. I know for a fact that if you put all those kinds of things into us ... your immune system will be damaged. That seems to be an accepted fact from America now. I don't have any family case history of MS. Now, the MS specialist that I've seen has said it's not genetic, but if you've got it, a cousin, an aunt, an uncle, whatever, somebody in your family, even if it's from a couple of generations would have had it. Well, my parents remember their great-grandparents, which is going back to Victorian era, almost. My parents

8. Physical Training Instructor. Many of the veterans I spoke to said that they were or had hoped to be PTIs. Amongst privates PTIs are respected as they are seen as the fittest in the forces.

were born before the Second World War in something like '38 and '39 ... So if they can remember their parents and their grandparents and their big, extended range and they know that there has never, ever been, on both sides of the family, any history of MS. So all of a sudden I'm looking at the facts. Now, I've had all these different things put into me. My immune system has been damaged. Well, how did that happen? I know I've got MS, there is no history of MS, so it's a direct result. It's indistinguishable ... It's a whole hodge podge of recipes all mixed together and cooked ... I think MS is intricately woven into GWS because it's immunological. It's motoneurone type damage, isn't it? I'm 36 as well. This came on coming up for two years ago, now. So, its, they say people start getting MS from 30 plus, but its unusual under 40. You do get the odd young person with it, but it's rare. You know, so that's another thing. Gulf War veteran, yet another first, you know?

For Lee, MS is a threat, but he only succumbed to it as a result of his damaged immune system. It is as though illnesses are incessant, but one is aware of them only when one's immune system lets one down. Veterans often talk about illnesses "lying dormant", under control until one's immune system is weakened as theirs was. It is as if one is always potentially ill, but illness only takes hold if the immune system is compromised. Contained in Lee's narrative is also his attempt to make sense of that which seems inexplicable. Getting MS simply does not *make sense* to him, particularly when he looks at his family history. Many of my informants suggest that the particular illness they suffer from was not present in their family, and, thus, another, more mysterious cause must be implicated. Furthermore, Lee stresses that his illness is "rare" and "unusual" in a man of his age, suggesting that there must be a peculiar element at work. Indeed, many veterans stress the unusualness of their illness, illness combinations, and/or age of onset. GWS provides them with a theory of causation that makes sense of the extraordinariness of their illness experience as well as it allows them to draw in disparate experiences and symptoms.

Non-believers point to the fact that symptoms emerged at different times depending on the individual and that there was no pattern in terms of symptoms. It is the individual nature of each person's immune system that is key to the explanation for this suggested irregularity. Narratives of GWS often stress the individual nature of all bodies and illness. One may have a propensity to cancer whilst another may have a propensity to MS. The immune system mediates this: once the immune system is weakened it leaves the individual vulnerable to their specific threats. So what determines who gets what? Just as there is a genetic element to the immune system, genetics also plays a key role with regard to determining propensity of diseases.



Many veterans suggest that the Gulf War and its exposures was a sort of trigger for dormant illnesses lying in wait within their bodies. Thus, there is anxiety about that which lies without the body, but dangers also lie within. During an observed assessment at the GVMAP, a patient explained that he had come because he had recently been diagnosed with a back condition. He said, "I have theory of my own. Why I have been referred here is my slight concern that what may have triggered it is service in the Gulf. From what I understand of the condition it is triggered by something. A colleague of mine had the same thing and it had been triggered by food poisoning." The doctor responded to his concerns by saying:

Your longevity will not be decreased because of being in Gulf. There is no increase in mortality due to disease; there is a slight increase because of violent death and suicide ... Tell your wife to be absolutely reassured ... If the Gulf had been a trigger, one would expect the illness to have appeared much sooner ... Had you not gone to the Gulf you would still have got it. Food poisoning is not a trigger, but the individual will say that it is that – it is what is linked in his mind. Do you feel reassured?<sup>9</sup>

The veteran responded that he did.

One veteran, Frank, suggests GWS is the result of an entirely new entity. The person and their immune system has never seen it before and thus, is unable to fight it, drawing on ideas of recognition.

I think it was something out there that hasn't actually gave us all these complaints, but hit the triggers. You know, like they say everybody is born with cancer and ... something happens and that triggers it all off. One of the doctors that says that to me. I ask how did I get this ulcerative colitis. They say, "you were probably born with it and something triggered it." [...] The linear IgA thing, what's triggered that? It's maybe something out there. Because nobody goes there. Nobody actually goes out and tests. The thing with the Ebola virus, they know it's out there. They don't know the source for it. They don't know where it starts from, they know it's a virus. My theory is there's something out there which is bad news, nobody's ever seen before. The way that the Bedouins and Arab people and Islamic law, what they do as soon as somebody dies they're buried. You've got a couple of hours and they are down under. So there is no autopsy. It could be that they are immune. Like ulcerative colitis is unheard of in the Middle East. So that is my theory. So I went to the MAP, they are looking for known diseases. Something they can say, "oh yes". But if it's something they've never seen before that is wholly brand new it's going to by-pass them. They will not say,

9. This is not a direct quote as it is based on notes I took during the assessment.

“oh, what’s that”, because that’s not what they are looking for ... I would say it [GWS] was a variety of illnesses that people would have got anyway that have been triggered by something out there.

Frank sees the illness as something entirely unique, an entity unknown to standard medical science. For him, the illness occurred because they were in unknown and uncharted territory. He believes there are areas in the world that are risky areas. Frank later told me that he knows it was the Gulf that made him ill because it was “the only place where [he’d] been somewhere new”. He said that after the Gulf he had only been in Germany and the UK; the only other “foreign” country he had been to was Canada. Thus, “foreignness” is a hazard in his view. He further suggests that the desert, a place where “nobody goes” is an extremely dangerous place. He reported seeing “weird” things in the desert – strange animals and plants – thereby emphasising the abnormality of the region. The body – and its wall of defence, the immune system – is unable to adapt to such new demands. The illness itself evades doctors. It is almost as though the bodies of Gulf War veterans are beyond the realm of medical science, as whatever has happened to them is so entirely unique and new as to baffle modern medicine.

Hooper sees the role of the immune system as central to GWS. He suggests that the failure of the immune system allows illnesses which are normally under control to overcome the body. During a meeting about War Pensions with a Gulf veteran Hooper focused on the possible presence of the Epstein-Barr virus, a ubiquitous herpes virus that most of us have been exposed to once we reach adulthood. The virus has been implicated in Chronic Fatigue Syndrome and a number of other illnesses. He says, “Can get it [Eps-Barr] from the vaccines ... Is he positive for Eps Barr? ... One of the things that happened with all the lads, is they came back with Eps-Barr. We all have it, but immune system keeps it under control like Herpes- we all have it but when [the] immune system goes down it breaks out.” It is as though immune systems and bodies are active, constantly keeping almost inevitable illnesses at bay. Illness is a persistent presence both within and without, but it is only when the immune system is weakened that one’s illness takes hold. The immune system no longer provides resistance. Once this occurs there is nothing one can do to prevent further failure. The idea of the immune system giving way under the pressures of twentieth-century life is not a concept unique to GWS and is found throughout contemporary health beliefs.

### *The Immune System as Arbitrator of the Psychological*

As mentioned previously, the rejection of any psychological factors is central to the debate about GWS. Placing discussions and theories of GWS in the discipline of immunology and genetics provides the basis for such a biological, medical explanation. However, explanations which prioritise the immune system allow for the inclusion of psychological factors without dismissing the physical premise of the condition. During my interviews I would ask if they thought emotions or state of mind could affect one's health. Many denied a connection; others suggested that this could be the case, but felt it was not a direct relationship. The relationship is seen to be mediated through a lack of sleep. The immune system is understood to work ineffectively if one is tired, but emotions do not directly affect this. Frank explains this relationship in response to the question: "do you think one's state of mind or one's emotions can affect one's health?"

Yes. If you are emotionally disturbed or depressed or something is really playing on your mind then it will effect your sleep and I think sleep is a great healer of things. Recharge your batteries. I learned that in the army. If I had any spare time I would spend as much time as that asleep. Sleep and eat. Get it while you can because you don't know when you are going to get it again. The longer I go without sleep the worse I really feel. My back hurts more, my stomach creates havoc. You need to rest for your body to recharge. And when your body recharges it helps your immune system to build up as well. Because I am quite drained, anything my kids bring home from school I catch it. Also think that some people can think themselves not well.

Others suggest that emotions and feeling "low" or depressed can reduce one's immune level, making one more susceptible to illness. Some veterans suggest that emotions lower the immune response because the body will be "concentrating" on other things. It is as though the body only has a limited amount of resources and if they are focused on one thing they will neglect another part of the body, such as the immune system. The connection between emotions, immune system and health has become widely accepted, particularly through the understanding of stress and has developed into its own field: "psychoneuroimmunology". Some recent GWS studies have suggested that multiple simultaneous vaccinations in stressed personnel may cause future complaints, particularly allergies (Rook and Stanford 1998; Rook 2002). Thus, it is understood that stress affects the immune system which makes it more vulnerable to additional assaults.

### *Vaccinations*

Vaccinations, which are commonly approached with anxiety, are seen as the primary cause of the illness. Vaccinations are known to affect the immune system directly and are seen to inject illness (in a weak form) *into* the body. A theory that emphasises the role of vaccinations enables veterans to account for a number of apparent anomalies, such as why are there a fair number of GWS sufferers who never went to the Gulf. The primacy of vaccine damage also provides a way to discuss levels of illness in individuals (i.e., those who had *all* exposures may be more ill than those who had less). From an early age we are aware of the immune system through the process of vaccination. We are taught that we can support and teach our immune system. Vaccinations are seen as introducing something to the immune system so that it is able to recognise and respond to it in the future. Seen as a kind of education programme for the body, vaccines are given to prepare and strengthen the immune system.

A number of studies have found a link between GWS and vaccinations (Rook and Zumla 1997; Unwin et al. 1999; Hotopf et al. 2000). However, it has been suggested that these findings are inconclusive because recall of vaccinations is not always consistent with the patchy records that exist. Most of the discussions of the vaccination programme are clouded by veterans' memories of people reacting adversely at the time. There is no doubt that a small percentage of soldiers reacted to the immunisation programme. Some had swollen arms, some had flu-like symptoms for a couple of days, some were bedded down and, more seriously, a small number were casevaced<sup>10</sup> out. There clearly was a level of anxiety directed at the immunisation programme at the time of preparation for the Gulf, and seeing people react negatively to the vaccinations added to the anxiety. Part of the anxiety about the vaccine programme was that it seemed counter-intuitive. In the run-up to the war strength was paramount, as one prepared for the war, while having vaccines was seen as weakening the body, even if only briefly. Since people understand vaccines as initially weakening the immune system, it is not surprising that they are seen as potentially dangerous. Vaccines are seen as introducing a dangerous entity, in weak form, into the body. Peter, for

10. Casualty evacuation. The term given to the removal of casualties or injured soldiers from the front line to their first medical station. In my discussions this term was used to describe the procedure when a soldier was flown out of theatre due to an adverse reaction to the inoculations.

example, sees a vaccine as "the introduction of the poison itself so blood cells can create antibodies to attack it". Another veteran, James, suggests that vaccines "put disease into the body, a little bit in and fights disease. It's safe on their own, but if you combine them they might be dangerous."

Veterans describe vaccines as a kind of training exercise for the immune system. Vaccinations introduce a small amount so that one is prepared and properly trained "so that you are prepared for the bigger version". Veterans emphasise the importance of recognition with regard to immune system response. Vaccines introduce information to the body so that it is later able to recognise and respond to the disease. The immune system is thought to have a kind of memory, so once it is introduced to a threat it will remember it and be prepared to fight it in the future. Boosters are seen as reminding the immune system of something it was previously introduced to, as the immune system will sometimes "forget" over time.

Soldiers are constantly given vaccinations and it is seen as an inevitable and regular aspect of service. Indeed, vaccinations are part of a soldier's regime and they can also be viewed as similar to other kinds of training exercises. Just as the soldier is prepared by small training exercises, so the immune system is trained by vaccinations. The vaccines given to soldiers are part of the process of creating the "proper" soldier as seen by the forces, the MoD and the government. As Martin (1994) suggests, since vaccines are perceived as a kind of education for the body, it is not surprising that some will not want such state-sponsored education. Accepting vaccination means "accepting the state's power to impose a particular view about the body and its immune system – the view developed by medical science" (Martin 1994: 193). In this case it is the view held by the MoD so it is even more loaded and political.

Some talk about the immune system being killed off or "stuck down" by the vaccines. One veteran described the immune system as held down and prevented from working. Veterans also stress the unnecessary aspect of the vaccination programme. In the end, there was no attack of anthrax or plague, so their immune systems were prepared for something that it never met. Veterans' statements suggest that vaccines, if unnecessary, block up the immune system. It is as though there is a limit to the resources of the immune system and the vaccines given to them in the Gulf distracted the immune system from doing other jobs.

As Martin (1994) found, some people wish to avoid the system of "state education" for their immune systems in the form of vaccinations. By doing so they are developing a positive view of what their health is.

This view “shares with immunology the basic notion of the body as a training ground for the immune system, but it denies the benefits of crash courses” (Martin 1994: 202). In such a view, a vaccine, “bludgeoning the delicate adjustment of the finely tuned immune system with antigens at a time when there is no actual threat, could easily be seen as something undermining health” (Martin 1994: 202). Martin further points out that whereas people may see their immune systems as adaptable and flexible, this can be contrasted with the rigid, unchanging state. So a vaccine policy which is planned and administered by the state could be expected to share its characteristics – sluggish and inflexible, unable to respond to individuals according to their health needs (Martin 1994). This may be particularly the case of the MoD and the military, who are often portrayed as both inflexible and malevolent. Indeed, my informants often suggested that the routine immunisations did not take into account individual differences such as weight.

### *Overload*

The concept of “overload”, with the body giving way to the stresses of twentieth-century life is a common theme in illness narratives of CFS and other new illnesses (e.g. see Steincamp 1989). Many of my informants explain that the immunisations and other preventative measures taken were simply too much for the body to handle. Many also stress that there were numerous vaccines given in an extremely short space of time. It is as though the body was unable to respond to the sheer amount of information given to it in one or two “training sessions”. Veterans also express concern that the vaccines and other exposures may have had a “cocktail effect” where they reacted in some way to produce a new, unknown entity. Paul explains:

I think giving a cocktail of so many chemicals are absorbed into your system. The immune system has basically collapsed and can't fight off what's been given. If you are given the flu jab you are given the flu, a small piece of the flu, to fight off the flu. Anthrax and Botulism ... it's the same thing. And malaria, NAPS, BATS<sup>11</sup> and whatever was out there like that dump. And don't forget the oil well fires ... the MoD saying that didn't happen ... To do with your health and fitness ... it's permanently damaged the immune system. I can't shake things ... Dr Jamal has proved that through his work ... I think it's [the immune system] collapsed. I think the immune system ...

11. Biological Agent Treatment Set. Preventative medication issued in the event of an attack by a biological weapon. Although it has been widely stated that no UK troops took BATS, a number of veterans claim to have taken them.

it's like a computer. Too much at one time going on the net, too many people logging on, for example. It collapses. It just can't take what's being given. Too much work load. It breaks down. Failure.

Gulf veterans talk about the body not being given time to recover before the next vaccine was given. There is a notion that the body needs time to react, rebuild and respond before it is ready to be educated again. They suggest that if the immune system is not given time it will be exhausted and unable to bounce back. As Lee suggests:

Well, I know it's like nowadays with the flu vaccine for the old people you go along, park your zimmer frame up, get jabbed and you come out. When you walked in the surgery you think OK, you get your flu jab and obviously it puts a little bit of it in 'ya so you can get the antibodies. You might get a few signs – runny nose, sore eyes, whatever. However colds tend to affect you most it will maybe come out. Because the obvious symptoms that you'll get that's your body combating it. And that's how it works. I mean, I did my RMA course, which is the medical course although I wasn't a medic, so I know a little bit about it. So you get a little bit in you so you can make your own antibodies to it. That's fine. Your body can cope with that. But when you've got *multiple* ones whizzing all around your system – the white blood aren't Linford Christie. There's not enough of them to deal with all what's in 'ya. You cannot keep putting foreign substances into a sealed system without problems happening. Its like hydraulics, it's like a car. You can't just keep filling up with petrol. It will only take so much ... Any sealed system can only take so much and that's the same with things like that. They overloaded the system that couldn't cope.

There is a point of saturation, where the immune system with all its flexibility is unable to continue reacting. It is almost as though there is a limit of elasticity. When the immune system has been asked too much and is overwhelmed it loses its ability to adapt. It is as though the bodies of veterans were not able to "take in" the education of each vaccine before being hit with another. Such exhaustion is permanent, with the immune system never able to recover. Discussions of overloading the immune system are often linked to the current debate about the MMR vaccine.

During the time of my fieldwork, vaccinations were once again in the news. The MMR vaccine was often the focus of news stories and public concern. Not surprisingly, veterans often voiced their concerns about the MMR for their children and linked the debate about the MMR, a multiple vaccination, with the theory of their illness. The furore around the MMR vaccine is used to justify their concerns and adds weight to their argument of the role of the vaccines in their illness. As Harry noted:

I think the large amount of vaccines in a short space of time must have had a knock-on effect to your immune system. I mean, I think it's associated with the MMR and things like that. Giving a lot of thing in a short space of time which is the British medical advised the MoD not to do that.

Ben also compares his Gulf War experience of multiple vaccinations to the current debate about the MMR vaccine:

I think that the fact that the drugs, the injections we had to take, we took them all in such a close proximity. Thinking about it logically, thinking about the problems that they are having with the MMR vaccination, the cocktail of drugs given to people ... again, nobody is admitting that there is a problem, on the government side of it. They have statistics showing that people have been made ill through it. I think look at these drugs that were given: anthrax, bubonic plague, God knows what.

Although most suggest that they were concerned about the MMR, they said they believe vaccinations were important for their children and that they would prefer single vaccinations. I was, however, surprised at the number who suggested that they would not or did not vaccinate their children. Many argue that it should be a parent's choice and discussions were placed in discourse of rights, liberties and control. Veterans suggest that parents would be more aware than the doctors if their children were "susceptible" or vulnerable, so they should have the right to choose whether or not to vaccinate. This resonates with Polotrak et al.'s (2004) investigation into parental attitudes about the MMR, which revealed that parents felt they could assess their child's unique vulnerability.

### *Self versus Non-self*

A central concept in immunology is the ability of the immune system to "differentiate between 'foreign' material (non-self) and the body's own tissue (self). The ability to make this distinction is crucial" (Isenberg and Morrow 1995: 2). The state of permanent protection is based on the immune system's ability to make this differentiation. In *Friendly Fire: Explaining Autoimmune Disease*,<sup>12</sup> Isenberg and Morrow (1995) claim that the most important role of the immune system is that of self-defence. In this popular book meant to explain auto-immune

12. Interestingly, I had called early papers on the subject of GWS 'Friendly Fire', unaware of this book. As one can see the name immediately conjures military images as well as the idea of one turning on one's own side through misrecognition.



diseases to the general public,<sup>13</sup> military metaphors prevail, as does the emphasis on the immune system's ability to recognise self from non-self. The authors argue that there "are 'enemies' both without and potentially within the body. Thus the immune system has evolved to ensure that foreign microbes can be recognised and speedily destroyed" (Isenberg and Morrow 1995: v).

The immune system is a cultural construct; the way we conceive of it is influenced by our understandings of the world. Our notions of what a "culture means socially are identical to our notions of what a culture is clinically [...] That our immune system takes part of the body as its own enemy is as much a statement of culture (in both a social and biological sense) as it is a description of something that is actually observable" (Napier 1992: 151). Veterans' concerns about the immune system are an extension of their concerns about body boundaries. Indeed, immunity to a large degree is what "establishes body-image boundary as much as what threatens it, and, since body-image priorities are cultural phenomena, so are the mental constructs that we call 'immune systems'" (ibid.).

As we have seen, the immune system is perceived as something inside the body which protects it from disease by recognising and fighting that which is dangerous. However, Gulf veterans see their immune system as failing in this regard. The immune systems of Gulf veterans are simply not working correctly, if at all. This results in the immune system no longer being able to fight, or even recognise that which it is supposed to fight. As Stan, a non-deployed Gulf veteran, explains, "The immune system is basically the body producing chemicals to fight against attack from outside forces. Body is just trying to defend itself to survive. System is not what it should be so it'll get you."

Veterans mainly discuss their immune system as giving up, but they simultaneously talk about it as being active in another way – in fighting against itself. This kind of activity arises out of a lack of control. The immune system is not behaving as it should and is not doing its duty. Aaron, a non-deployed veteran,<sup>14</sup> discusses his understanding of his illness:

13. I was informed by Dr Andrea Stockl, an anthropologist studying the auto-immune disorder, Systemic lupus erythematosus (SLE), that most of her informants had read this book and that it was described as their "bible".
14. Aaron left the army in the 1980s but has joined the association because he feels he has the same illness as other Gulf veterans. He believes he was injected with the same things as Gulf veterans were. He sees GWS as part of a much larger illness of many ex-soldiers. Although he was accepted into the group, they are now keen to distance themselves from him. It is likely that this is because accepting him as having GWS weakens their argument of the uniqueness of the Gulf War and GWS.

The immune system is to fight illness, disease, bacteria. For it to suddenly turn on itself, which is what mine has done, I mean, how you get from one day you are working fine and the next day your face is pure white, you've got a blinding headache, you can't see properly, your bowels have gone. And they find out there is not enough oxygen in the blood and then they find out why. It's because the immune system is destroying the oxygen in the blood. I mean, something has gone wrong for it to make that sudden change from attacking illness or bacteria to attacking itself.

Aaron sees his immune system as actively fighting against itself; it suddenly changes its duty. Before, when he was healthy, the immune system fought against illness, but now it is unable to recognise the difference between self and other and, instead, attacks itself. Claeson et al. (1996) found that the "concept of the boundary between self and non-self is a touchstone for broader social meanings. Since [they found] such concepts so commonly in interviews, it raises the question of whether the central role of boundaries in current research immunology is not culturally based in its inception" (Claeson et al. 1996: 114).

Veterans and their advocates stress that they suffer from "auto-immune" diseases, where the body does not recognise its "self" and as a result interprets as foreign and attacks itself. Auto-immune diseases occur when the body inadvertently attacks its own healthy tissues – described in immunology as "self-destructive illnesses". During a talk he gave to the veterans' association, Hooper spoke about a scientific study<sup>15</sup> which suggested that 12 per cent of US veterans who were given vaccinations, but were not deployed, had GWS. He further suggests that,

Anybody who knows anything about vaccines knows about ... the auto-immune diseases that you get. How many of you have got arthritis? And how many have got auto-immune diseases affecting the skin? Any of you got lupus? You know, these are the sorts of things you would expect. Diabetes, another one [that] can be auto-immune generated. There's a whole range of auto-immune diseases which are well known. Multiple sclerosis – damage to the central nervous system, you know. They are all there. And this is what you would expect from vaccine damage.

Hooper suggests that the vaccines given to Gulf veterans triggered an immune response which resulted in auto-immune diseases: that the bodies of Gulf veterans are turning on themselves.

15. Unpublished study by Lea Steele

In her work on the cultural life of immune systems, Haraway suggests, "disease is a subspecies of information malfunction or communication pathology; disease is a misrecognition or transgression of the boundaries of a strategic assemblage called the self" (1991: 212). Veterans submit that whatever happened to them in the Gulf resulted in their bodies being unable to make this differentiation. Martin found that:

[The] portrait of the body conveyed most often and most vividly in the mass media shows it as a defended nation-state, organised around a hierarchy of gender, race, and class. In this picture, the boundary between the body ("self") and the external world ("nonself") is rigid and absolute ... The notion that the immune system maintains a clear boundary between self and nonself is often accompanied by a conception of the nonself world as foreign and hostile. (1994: 51)

Thus, we can see how military metaphors follow easily from such distinctions between self and foreign, hostile entities.

## Military Metaphors

Although my informants did sometimes use other metaphors (house, computer) for the immune system, the majority of them used military metaphors. In many of the above quotations one can see such metaphors being used to organise and make sense of illness. This is not unique to military people, however, as immunology is dominated by military metaphors. The potential for embodying the images that the immune sciences presents us with "as they trickle down through *National Geographic* and *Time* (Haraway 1993; Martin 1994) – including commonly militaristic ones – is real (Napier 1996: 335)" (Wilce and Price 2003: 56). As we have seen above, veterans talk about their immune system not doing its duty, not behaving, fighting, as it should. When they describe their immune systems they imagine them as comprised of sentient beings, like soldiers: as Steve describes, "I've seen it in books: billions of little soldiers under a microscope fighting another lot of soldiers and ... the vaccine is the little soldiers."

Ed uses a number of metaphors to explain how he imagines what happened to his body when he was injected with the vaccines for the Gulf War.

It just feels like it had the adverse effect [...] Like a wall coming down, I think. Like the enemy hitting you, attacking, you know, I've got my defences. Like a game of chess, I suppose. The other side of the board

attacking me and with him so easily knocking my defences down without me being able to fight back, totally defenceless ... Because there were so many at once and because they tried to do ... not too many chefs spoil the broth, type of thing. But too many trying to do different things without thinking about it. And it went totally adverse, it went totally the other way. It's like an army colonel planning a battle and not planning it properly and everyone going in without a clue of what to do. And it's all gone wrong, basically. It's just breaking down. It's just giving up so easily. The body is not being able to fight it. Why is the body not fighting it? Where are my defences gone? Surely I should have something in reserve to help.

Earlier in his discussion, Ed explained to me that whatever had been given to him had "killed off" or "stuck down" his immune system and prevented it from "doing its duty". He also described a cold as a "big battle" inside himself. In his explanation above, Ed discusses confusion: he imagines his body in a state of chaos, with "everyone without a clue of what to do". He imagines that there was too much happening and the body, which could not respond appropriately. Contained in his explanation is the sense that there is a lack of communication resulting in failure. This theme of miscommunication emerges again and again in veteran's narratives about the war itself and their illness. As Ben says:

I've been given all this stuff in my bloodstream and my body is designed to attack it and that's what happens. That's the way I look at it in my head. These white cells, or whatever, are attacking all the horribly nasty stuff. In fact, did you ever see that film with Raquel Welch? That's how I imagine it ... Because I had so much, I imagine I didn't have enough antibodies to attack this stuff. And so, it was like, a thousand men defending against 10,000 men. No matter how much I had in my body, I don't think I'd have had enough to have coped with the amount that was attacking it. So that's what's going to make you feel poorly. Your body can only cope with so much ... [How do you understand vaccines as working?] You get given a certain amount of the disease or whatever it is that they are trying to protect you against. So your body's immune system can attack that. Fight against it. Figure out what it is it's fighting against. And create its own immunity against it happening again. So, "oh look, I've got one of my, ah, antibodies here in my body. It's attacking this horrible thing. Ah, I know what it is now and there are plenty of us here now. There are 10,000 of us attacking a thousand of them. All right, we've beaten you. What is it? Ah, we see what it is. OK then, we'll take a little bit of that and stick it in our memories, tell our whole body about it so next time it sees it, it won't let it hurt me".

After Ben's explanation of what happens when one gets a vaccine, I asked him what he imagined happened in his body when he was vaccinated in preparation for the Gulf War:

Well, I never thought about it in this way before, it's quite good. I've got a thousand of me over here, 10,000 over there now, it's attacking all these things. It says, "OK that's what that is". All right, you might have one little cell say, "oh, I've beaten him now", you know, "I've beaten him up, I've done all Pleasant Stead<sup>16</sup> now. I want to go on to Raquel Welch. No, but I'll tell the rest of my body now. Hang on a minute, my mate over here is telling me over there that he has just eaten him over there and he wants to tell everybody that this is the one to fight against". And just imagine it, it's like Chinese whispers, I suppose. You've got ten people in a room, say ten different vaccines. They've all got, they've all done their jobs but they are trying to tell each other how to fight it. And then they say, "well, hang on a minute, we haven't got the resources to tell everybody in our body to tell them to fight all of these at once. Should we tell them to fight one of them, or fight a little bit at a time. Or what should we do?" So all of a sudden there is a hell of a lot of confusion. They, ah, might even get mixed up, saying, "well, hang on a minute, did he tell me this is what we're supposed to do to fight this and to fight that?" OK, they aren't reasoning, thinking beings, but they could get confused in their signals. Because there are so many at the same time. Or very similar vaccines or things. Or too many and they haven't got the resources to fight it. I mean, you go to war, you fighting an army of 50,000 men, you've got 10 where are you going to get the rest from? Well, you haven't got them. What are you going to do? You can run away or you can cope as best as you can. You can't do it.

Ben expands on the military metaphor and the theme of miscommunication. Martin (1994) showed that in the media military metaphors abound, but there are also descriptions of the immune system as a "regulatory – communications network" (Schindler 1988: 1). The body is seen as "an engineered communications system, ordered by a fluid and dispersed command-control-intelligence network" (Harraway 1989: 14). My informants tended to collapse these two metaphors. The system, a military system, is held together by systems of communication and feedback. I would suggest that as military personnel, their jobs focus on organisation as well as the efficient flow of orders and information down the lines of command. It is not surprising then that when discussing their unresponsive and broken bodies they make use of this kind of metaphor.

In her work, Martin (1994) found that people used military images regardless of their gender, age, race or other social features. She felt that this was partly because of the omnipresent imagery in the media, although the kind of society in which different people live may also be

16. Character from the movie *The Fantastic Voyage*. Ben was not the only veteran to talk about this movie in his discussions of the immune system.

important. Martin wrote: “*all* the examples that struck [her] as the most elaborated, vivid departures from military imagery came from people in their late teens and early twenties, people coming of age at a time when cold war assumptions are being drastically shaken and a new sensibility about how the body relates to the world may be arising” (Martin 1994: 71; emphasis in the original ). Thus, it is not surprising that military metaphors abounded amongst my informant population, whose view of the world had been dominated by their military careers, war and the preparation for war. Their use of military metaphors was quite specific, focusing on themes of quantity and strength. Interestingly, they do not appear to use themes which are widely used when discussing the Gulf War, such as intelligence and technology. Their narratives are likely to reflect their own experiences of war, as illustrated in the next section in depth.

### *Friendly Fire*

The military metaphor is expanded to discussions of friendly fire, where the enemy is one’s “self”. This relates to the discussion above, which situates immunology discourse in the central distinction between self and other. Indeed, I would suggest that discussions of self and non-self in the GWS context could be collapsed into discussions of friendly fire. The Gulf War was a war with few coalition casualties. Media reports enthusiastically reported the “smart” and “clean” war which resulted in very few deaths (not reporting the large casualties on the Iraqi side), yet more soldiers died in friendly fire incidents than were killed by enemy fire. The “blue on blue” incidents were powerful stories. During my interviews I was surprised by how many people discussed the friendly fire incidents and their connections to them. Although the number of such incidents was limited, it appears that an inflated number of people claim to have been involved to some degree.

The concept of one’s side fighting and killing its own people through breakdown in communication and confusion was often part of the veterans’ discussions. The term “friendly fire” has traditionally been used to refer to those injured by inadvertently targeted munitions from their own side. This, however, has been extended even further in the aftermath of the Gulf War. When veterans speak about their illness they not only use the friendly fire metaphor for the cause of their suffering, but they also talk about their illness as their body turning on itself – a kind of blue on blue. Drugs given to them by their medical officers, their commanders and their government is that which is killing them. That which is slowly killing them is a result of their own side’s

mistake or, worse still, purposeful sabotage. In discussing the side-effects of their Gulf War experience being passed down to their children, veterans often suggested that this was a kind of friendly fire.

As mentioned above, the central concept in immunology is the ability of the immune system to differentiate between "foreign" material (non-self) and the body's own tissue (self). Health is entirely dependent upon the ability to make this distinction. In their discussions of auto-immune disorders, veterans suggest that their bodies are turning on themselves, which could be likened to friendly fire: the body does not recognise itself as not the enemy. In his discussion of the vaccinations given to him in preparation for the Gulf, Ed says, "I just think they've done the opposite of what they were supposed to do, you know. I mean, they were fighting against each other. Whatever they gave us had a totally adverse effect because they mixed them together."

Science literacy is much more than merely knowing some basic "facts" and simple concepts (Hazen and Trefil 1991a: xix). Individuals use "facts" in very different ways; they often make them work with their particular local circumstances as well as express their most overarching views of the world (Claeson et al. 1996). Claeson et al. suggest that using metaphor to

[C]onceptualize the body may affect our conceptualization of social situations. Some theorists emphasise the interactive nature of the elements paired in a metaphor, so that when Dante says "Hell is a lake of ice," the hearer extends the association of "hell" to a "lake of ice," thus transforming both elements of the metaphor (Hesse 1961; Black 1962: 37). Through the use of a body/war metaphor we may not only be thinking of the body as naturally war-like, but we may also be thinking of the state of war as natural. (Claeson et al. 1996: 144)

When veterans discuss their illness in terms of friendly fire, they are explicitly commenting on their view of the world. Veterans see the world as full of threats: pollutants, genetic illnesses (such as cancer) and toxins, but the greatest threat of all is one's own government. Substances and institutions which we once thought to be harmless are now the purveyors of danger.

Although initial theories of GWS pointed to possible unknown chemical or biological warfare by Saddam Hussein, these theories were soon abandoned.<sup>17</sup> Instead, theories now point to known contamination

17. Not totally abandoned, however. Hayley explicitly states that GWS is due to brain damage which was caused by sarin on day four of the war (Wessely 2003).

by the UK government. The consequences of being wounded by your own side are greater those resulting from enemy action. The isolated cases of both the American and the British being wounded by Coalition forces, and anecdotal evidence, suggests that these personnel have experienced greater psychological problems than others (Wessely and Freedman 2006). One must also ask about the effects of being harmed by one's own side in terms of Gulf exposures and the subsequent development of GWS. Of all the exposures implicated, only smoke from burning oil wells was clearly the result of enemy action. It is worth noting that this is the exposure that has attracted the least attention. Veterans see the MoD and the government (including most doctors and scientists) as their main enemy. That which was friend and protector has turned on them and, indeed, is that which has made them ill. As Malcolm Hooper said to me during our first meeting, "As you can see all these things have nothing to do with Saddam Hussein except possibly biological. But we sold the cultures to him to develop. Our own enemy. We are the enemy." This comment resonates strikingly with Martin's report that in one television show, auto-immunity was described as "we have met the enemy and the enemy is us" (reported to Martin by Ariane van der Straten; Martin 1994: 62).

## Conclusions

Reporting that they *feel* and *know* their immune system to be damaged can be linked to their embodied experience. Recent studies have revealed that even within a medical establishment individuals "generally attribute feelings of vigour and vitality to a well-functioning immune system, and feelings of fatigue to poor immune function" (Booth and Davison 2003: 37). Petrie et al. found "perceptions of immune functioning to be unrelated to the concentration of serum antibodies or blood lymphocytes. Immune perceptions were strongly related to mood and in particular, feelings of fatigue and vigour. The experience of recent physical symptoms, while not as strong as mood variables, was also important in perceptions of immune functioning" (1999: 391). The idea of the immune system has become so embedded in popular culture that popular notions of one's own vitality and health are often expressed in terms of perceived immune function.

It is not surprising that Gulf veterans, whose very suffering is in dispute, would look towards the immune system to organise and legitimate their illness, since the immune system has emerged "as a field in terms of which all manner of questions and definitions about health are given meaning and measured" (Martin 1994: xvii). An aspect of this



shift towards immunology is that bodies and immune systems were seen as agile – no longer docile. Tauber (1994) shows that immunology “was born in the controversies of that fresh announcement that no species, including our own, was a static entity [...] it is always adapting, always changing. Thus, the very core issue of *identity* is for the first time raised as a problem. With the Darwinian revolution, a physiological ability to differentiate self from nonself must be postulated” (Tauber 1994: 2; emphasis in original). Central to notions of the immune system is the ability to adapt and evolve as one faces new challenges. Lay theories of illnesses such as ME/CFS, food allergy, MCS and others see them arising when the immune system gives way under the pressures of twentieth-century life (Shorter 1992). The threats to immunity come from toxins, pesticides, contraceptives, pollution, viruses, food additives, mercury, and so on. Even stress, a psychological concept, is accepted usually via its effect on immunity. The person and their immune systems are simply overloaded and unable to keep adapting.

The veterans’ discussions described above can be seen as examples of how people are engaged in producing what Geertz has called “local knowledge” – “the artisan task of seeing broad principles in parochial facts” (1983: 168) and “stories about events cast in imagery about principles” (Geertz 1983: 215). When people discuss the immune system they are revealing their conceptions of both bodies and other social facts. When veterans talk about their immune system as being insulted and degraded they are also talking about their position in the world. They are recounting their experience of being in and of leaving the military. Bodies which were once toned and prepared have become chaotic and weak. Their immune systems have reached their limits and no longer adapt. When veterans talk about their illness as their body turning on itself, they are reflecting their belief that their government has let them down and betrayed them, and also drawing on their experience of war itself.

Situating discussions of their illnesses in the discourse of immunology allows veterans an overall, inclusive theoretical model of their illness whilst simultaneously encompassing the overwhelmingly individual nature of the illness. Thus, any illness or symptom can be included in GWS narratives by way of situating it in the immune system. This understanding of the immune system is very important because it explains what is otherwise inexplicable. Through the immune system veterans are able to develop an inclusive and watertight system. They are able to relate OPs to vaccines and NAPS; they can relate different scientific themes and explain diverse outcomes. This theory is also able to explain why a proportion of sufferers never went to war. The immune system is a central melting

pot and allows them to make sense of the incoherent. In discussing the immune system veterans are also revealing their view of the world, their feelings of vulnerability and their experience of unravelling after leaving the forces.

**Part III**

**GULF WAR SYNDROME  
AS UNIQUE ILLNESS**

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## Chapter 5

# **VETERANS' ASSOCIATIONS**

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This chapter is not available in the OA edition due to rights restrictions. It is accessible in the print edition, spanning pages 125–153.

## Chapter 6

# THE DISAPPEARING MAN: NARRATIVES OF LOST MASCULINITY

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One day Rebecca said to me, “I think they are all turning into women”. This comment struck me and as I continued to interview GWS sufferers it took on more and more meaning. The issues of sex and reproduction appeared in sufferers’ accounts over and over again. Early in my fieldwork I observed a key meeting between Bob, an ill veteran (introduced in Chapter 3), and Malcolm Hooper, the veterans’ scientific advisor. The meeting was to prepare Bob for his war pension appeal tribunal the next day. Bob was attempting to increase his war pension by demonstrating that he had additional illnesses and disabilities which were linked to service. This meeting reveals the themes to be discussed in this chapter.

*Malcolm Hooper (M):* Also you talk about arthritis. What I’m getting at is that vaccines can cause arthritis. You should not be getting arthritis in your 30s. Is there any history of it in your family?

*Bob:* No.

*M:* Have you got muscle pain as well as joint pain or can’t you tell?

*B:* I can’t tell.

*M:* Do they mention fibromyalgia?

*B:* No.

*M:* [explains that fibromyalgia is pain in the muscle and that there are a number of points on one’s back. Points out these areas to Bob]. There are 18 points: if you have pain in 11 you have it. Others clearly have it. It is rheumatoid arthritis which is immune problem. What I think ought to be done by anyone who is intelligent ... you never had a hormone test, testosterone test et cetera. Key hormones influence development and

maturation of spermatozoa and masculinity. Lots of macho stuff with testosterone, that would exacerbate the problem. But nobody has looked at that. Other thing they've made a lot of is obesity. But you don't look obese to me.

*B:* I've put a lot of weight on.

...

*M:* What about your chest? Breathing all right?

*B:* Yes. But I have bitch tits. I told this to the Colonel when I told him about my facial rash.

*M:* Let me look at your rash. Looks like a butterfly rash, a lupus thing. What you call bitch tits – it's called gynaecomastia. But I don't see that in your records.

*B:* It's a bit embarrassing. I was told that the doctor won't do anything to it unless I get a lump in it.

*M:* Another vet had it and was too embarrassed to say anything. That would go with a hormone problem.

*B:* They put the bitch tits down to obesity. The doctor says on page 24 "he is very worried about his obesity and thinks he is growing breasts. He does not have gynaecomastia but is quite fat. He is quite depressed because of the war and needs drug therapy".

...

*B:* What about suppression of sexual urges? They offered me Viagra but I don't want it.

*M:* What they mustn't do is offer you testosterone.

*B:* What about mood swings, anger, violence. I've wrecked four phones. I've seen a psychologist for two years.

This transcript reveals the way in which discussions of GWS include issues about physical forms of masculinity. Bob and Malcolm discuss Bob's lack of libido and the fact that he is concerned that he may be developing breasts. They talk about lack of testosterone and hormone problems, but they also discuss his heightened aggression. In this chapter I will discuss how GWS narratives focus on physical manifestations of masculinity characterised by bodily strength, vitality and potency. I then interpret these findings by suggesting that GWS narratives express concerns about masculinity, or, more precisely a loss of masculinity.

## **Semen**

Foucault (1980) questioned why it is that our society perceives sex as not just a means of biological reproduction or simply a source of pleasure but, instead, as the central part of our being, the privileged site in which the truth of ourselves is to be found. Narratives about GWS

contain discussions of sex and reproduction and there is a high level of anxiety about these subjects. A unique aspect of GWS is its contagious nature: it can be passed by sexual contact, reproduction and even by living in close proximity with a sufferer. The main vehicle for contagion is semen. GWS sufferers believe their semen to be affected by their participation in the Gulf War. Thus, GWS does not only affect those who participated in the war, but also innocent members of their families. GWS is seen to permeate the veteran's body and to invade those of his loved ones.

### *Infertility*

A common theme in stories about the Gulf War is the concern that veterans may be infertile due to the exposures and preventative measures given to them. Abou-Donia, the GWS researcher discussed earlier, argues that the combination of chemicals given to protect Gulf War soldiers may have damaged their testes and sperm production, causing infertility. I found that this concern seems to be mainly contained in discussion by non-sufferers. This worry, for example, presented itself on a small number of occasions at the GVMAP. I also found that healthy Gulf veterans would discuss this as a possible and vague concern. However, discussions of infertility were rarely, if ever, contained in sufferers' own accounts. Infertility remains a dominant aspect of discussions of GWS in the media and had ramifications for the second Gulf war. In the run-up to the war in Iraq (2003) an article in *The Observer* appeared:

Scores of British servicemen heading to the Gulf are visiting sperm banks so their partners can still have their children if they are killed or rendered infertile by chemical or biological weapons ... Veterans' groups say they have had many inquiries from servicemen concerned at the possible effects of vaccines administered by the Ministry of Defence, apart from the danger of being killed or rendered infertile during fighting. The cocktail of chemicals, similar to that given out before the first Gulf War in 1991, is meant to guard against insect bites and Iraqi chemical and biological weapons. The MoD insists it is safe, but some veterans say it has been linked to problems of fertility in soldiers returning from conflict. (Harris 2003)

The article directly links the soldiers' concerns about fertility to issues about GWS; thus, we can see that infertility remains part of the public discourse on GWS.



### *Low Libido/Impotence*

Low libido and impotency are two of the most discussed symptoms amongst my informants. Veterans and their wives discuss their lack of interest in and inability to perform sex. Thus, the essence of masculinity – semen – is absent. They lack the ability to express and convey masculinity through the ejaculation of semen.

During my first meeting with the women who ran the veterans' association I was struck by how quickly their discussions turned to issues of sex and sexuality. During our first interaction, Rebecca complained about her lack of sex life. She told me that John had just been put on Viagra and that she was very pleased about this recent development. During this same meeting Kerry told me that she and her husband had not had sex for five months. "That's not normal", she said, "I could count on one hand how many times this year". During my time with the association I found this common complaint vocalised by wives of veterans. Indeed, on a number of occasions, wives would joke to me about their impotent husbands. They would tell me that they were going to "spike" their husband's drinks with Viagra. On one occasion whilst staying at Rebecca's house she told me, in front of her husband, that I should not feel threatened or worried about him coming into my room at night because he "could not get it up".

Roughly 15 per cent of my informants include "low libido" in their list of symptoms; far more, however, spoke about the condition. Many suggest that this has been a difficult aspect of their illness for them and for their partners. One veteran, Dave, said:

I think pride is something we have in common apart from the physical problems that I'm suffering now; psychologically it is very difficult. On a family level, one of the problems was problems with libido. People joke about it, but it's a very serious thing for one's partner. Something has decreased the amount of what we would call normal libido in a person of our own age. That can seriously affect whether you stay together. It leads to more psychological stress.

Another veteran, Sean, said, "I'm unable to have sex. I can't maintain an erection at all. Again, which didn't help my marriage."

Notions about low libido and impotency are often linked causally to NAPS tablets. Indeed, during and after the Gulf War, rumours abounded about NAPS tablets and their effect on one's sexual desire. NAPS tablets were also referred to by their medical name Pyridostigmine bromide (PB), and it is likely that soldiers made the link with the use of bromide in military mythology. Throughout

military history there have been persistent rumours that bromide was put in soldier's tea to lessen sexual desire, a myth which survives to this day. Such rumours originate from the Second World War, where soldiers were given bromide in order to prevent masturbation (self abuse) in order to ensure a good night's sleep (Jones 2003). It could also be interpreted that this was done to channel energy and potency, much like football players today abstain from sex prior to a game.

During an observed assessment at the GVMAP, the doctor discussed with a veteran the preventative measures taken in the Gulf. He asked the man about side-effects from NAPS tablets and vaccinations. He told the patient that he had heard from wives that NAPS tablets had "taken away their manhood" and that he had heard similar stories about malaria tablets in the Second World War. The patient, in this case, replied that he had no side-effects. Interestingly, I was told that the tablets caused permanent erections, but others reported they caused a lessening of sexual desire and drive.

### *Burning Semen Syndrome*

Although there is a concern about infertility and the lack of potency of Gulf veterans' semen as well as concerns about low libido, another common complaint is that veterans' semen is extremely powerful. It is seen as toxic and dangerous, a kind of concentration of all that they were exposed to. Thus, there is a contradiction contained in discussions of GWS, sexuality and semen. On the one hand semen and sexuality are impotent, on the other dangerously potent. Wives and partners complain that their veteran's semen burns them, leaving them with blisters and rashes. It is suggested that men sometimes feel it too, so that intercourse becomes difficult or impossible. A name has been given to this condition: Burning Semen Syndrome (BSS).

Only one of my informants directly listed BSS as a symptom, but almost all talk about the condition and refer to it as a major part of GWS. As it seems to have captured the imagination, we must ask why it is that some symptoms become and remain central components even if, it would seem, the majority do not experience them. Central to this is the fact that as an anthropologist I interpret symptoms differently. Whereas for others, the "reality" of the symptoms is key, for my interpretation the most important issue is merely the fact that people talk about them. BSS would be unlikely to be picked up or seen as important from an epidemiological point of view since few veterans report suffering from it and yet in my fieldwork this symptom played a major role. In order to make sense of this I look at what symptom

reporting is conveying, rather than focusing on uncovering the objective truth in them. BSS, impotence and infertility have all become intertwined with GWS narratives and become powerful markers of it. Thus, they are clearly communicating something meaningful.

BSS is often described as one of the oddest and rarest conditions associated with GWS, yet many of my informants speak about it as a central feature of the illness. Martha, a Canadian Gulf veteran emphasises that those contacting her are mainly family members inquiring about BSS and other forms of contagion.

I've come across others, significant others who are ill and they test positive for Garth Nicholson's mycoplasma test.<sup>1</sup> It doesn't just stop with the soldiers. Our kids are born with birth defects. Congenital defects or chemical sensitivities. It is clear there is something there. I'm sure you have heard from other veterans about burning semen. Why is it burning? Women call up asking, "What do I do?"; "Why is it that when my partner's semen gets on me it burns and makes a boil?" Durakovic says it's because of DU. This is not just like other wars where you got shot, you healed and you move on. Modern warfare is not like that. Our enemy is invisible now. Invisible enemy, we have invisible illnesses, and the government is trying to make us invisible. What are we leaving behind? It's not just us affected. The government is negligent about that. About the organ supply and the blood supply: we are leaving it behind (in the civilian population) ... [You mentioned that children are being born with birth defects and that partners are being affected. How does that happen?] Through semen and through our gear, what we brought back with us. It was covered in DU dust. Nerve gas on our equipment. Toxins have got into the semen. But I think it's mainly DU. For men the semen is toxic and contaminated. The men have pain in their testicles, prostrate problems; it's painful for them to have sex. I've heard of men who have to get up at three in the morning to have a bath because it's so painful down there. Women have menstrual difficulties; their periods are all over the place, miscarriages, birth defects, difficult pregnancies, hysterectomies. I know a woman, unfortunately she is too sick to meet with you, her breasts ooze greenish fluid.... Mainly it's the partners, the wives calling and saying that their husbands don't talk about it. Ninety per cent of the time it's the significant other – the partner, or the daughter. It's not the soldier. They are concerned about themselves. They wonder why there are problems with sex, the burning semen, why am I feeling tired all the time? Is what he has contagious? I'm always tired; I have what he has ... Those that were to get sick are sick. Now it's more in the families.

1 For a discussion of Nicholson's work see below.

Contained in Martha's discussion are a number of themes concerned with sexuality, contagion and legacy. At this point I will focus mainly on her discussion of semen and its contagious and toxic characteristics. Her other concerns will be discussed below. I have decided, however, to leave her narrative complete in order to reveal how these issues overlap and remain connected to one another.

Martha suggests that in her role as an advocate/expert she is now contacted mainly by partners of veterans who are concerned about their own health. She suggests that their semen is toxic and this is most likely due to contamination by DU. The enemy is seen as invisible, getting into one's very being and affecting the core of one's body. Martha focuses on this invisibility: "Our enemy is invisible now. Invisible enemy, we have invisible illnesses, and the government is trying to make us invisible." As veterans struggle with the imperceptibility of their illness, they talk about body fluids and the observable souvenirs of their illness. Birth defects and the rashes of burning semen are this invisibility made visible. Bodies of veterans have been made poisonous and this toxicity is, in turn, contaminating others. Martha suggests that this contagion could even be implicating the average person via the blood supply and organ donation arena (see Chapter 3). For veterans something as natural as having sex with one's partner is risky and dangerous. Sex is painful and difficult: their semen venomous.

Despite the medical community dismissing BSS, it has been the subject of a great deal of interest. The US Department of Defence funded a study in 1997 looking into the immunology of BSS, on the hypothesis that it is a quasi-allergic phenomenon in which women have become immunologically sensitised to their husband's semen, which has become toxic through Gulf exposures. The study investigated "seminal plasma hypersensitivity" in 188 couples with the complaint, who responded to an internet survey; five such couples were then studied. Results were inconclusive (see Bernstein et al. 2003).

During a focus group with John and Jack, the sexual nature of the illness took a dominant role. When I asked the men what symptoms were common to GWS sufferers, they listed a number of symptoms and then Jack said:

While we are on the subject of children and what sort of symptoms do you suffer, a lot of Gulf War veterans suffer from things like burning semen. A lot of them have various diseases that they are passing on to their partners: an abnormal amount of sexual diseases. Their girlfriends and wives [are] having a lot of problems in the genital areas ... burning semen and various diseases ... I know these things are happening to me. I know that these

things are happening to veterans, but why they are happening? I don't know. I don't have any answers.

John continues the discussion by developing the ideas of sexual diseases and GWS: "Herpes simplex is a secondary problem that DU can cause. That's why many, many veterans after the Gulf war came down with herpes-type problem and passed it on to their wives and burning semen syndrome." Jack then adds a personal element to this discussion:

*Jack:* You still have it, still have the problems today. Burning semen and herpes and all that stuff. When I was with my last wife, she couldn't understand it all. At first she thought I had an affair because she came down a few times, on a few occasions with this disease. With herpes, like I say, I don't understand all this medical stuff.

*John:* I mean there are other explanations for things, but you've got to ...

*Jack:* Like all those camels we made love to.

*John:* Yeah. [They both laugh]

Reminiscent of AIDS, GWS is sexually transmitted. Herpes and other STDs are understood as being part of GWS. However, these veterans suggest that whereas they transmit these things sexually, they themselves contracted the illness without sexual contact. Again, depleted uranium is implicated in both herpes and BSS, a connection I will discuss below.

The only veteran who told me directly that he and his wife suffer from BSS further suggested the hostile nature of his sperm. Ed, the veteran discussed at length in Chapter 3, told me that his wife had a miscarriage in October 2000 after they had tried for a year to get pregnant. When she had the miscarriage they were told that his sperm had attacked her egg. I asked him to describe what he had said were the "strange circumstances" of the miscarriage.

Yeah, it was the chromosomes, I had double the chromosomes, I mean I think you are supposed to have 36 or 37 chromosomes for male, but I had 70 something. I had double the chromosomes. And they were attacking the egg, the fetus, they were fighting each other. And they put it down to a, what's called a blated ovum. Ummm and they, I mentioned the Gulf war because I was pretty upset because I was almost 100 per cent sure that it was down to that. But they were saying, oh no it could be natural. If a woman's body is not ready for a child that will happen. But I wasn't convinced.

Ed now has a healthy child; however, he remains confused about what he saw as the odd circumstances surrounding his wife's miscarriage.

Ed's semen is active and hostile, attacking what it should not: his wife's egg. It is extremely potent, a notion that extends discussions of toxicity and BSS.

### *Women Contaminated through Men*

BSS represents a direct transmission from the sick veteran to his partner, but other symptoms such as fatigue, pain and confusion are also conveyed. It is unclear, however, how this may occur. A popular theory proposed by Garth Nicholson suggested an infectious agent; this is the theory mentioned in Martha's quotation above. Celebrated by veterans and their advocates, Garth and Nancy Nicolson's work is often used to explain GWS, particularly its contagious element. The biochemists became involved with GWS when their daughter, a Gulf veteran, became ill. The Nicolsons themselves had experienced episodes of symptoms, which they believed were caused by GWS contracted from their daughter. They believe that infections could be transmitted to immediate family members who subsequently display similar signs and symptoms and are often diagnosed with CFS and/or fibromyalgia. Their theory is that mycoplasmas, a type of microorganism, had entered the bloodstream of soldiers, possibly as a result of genetically engineered Iraqi weapons or contaminants from multiple vaccines. Nicolson claims to have evidence that HIV was mixed up somehow with the veterans' mycoplasma. GWS is not a unique syndrome, he argues, but is, instead, linked with CFS and FM. Furthermore, he believes it to be treatable through a course of the antibiotic doxycycline. Interestingly, although heralded by veterans, none reported having the treatment.

In addition to reporting that semen burns them, veterans' partners would often tell me that they suffered from other symptoms; again, semen is seen as the contaminating agent. The fact that GWS implicates family members further provides a rebuttal to those who suggest that GWS is psychological. It is understood that women can be contaminated and affected physically by GWS through sexual contact with their GWS sufferer partners. As mentioned above, the contagion of men was emphasised by the female organisers of the association. When we first met, Rebecca told me almost immediately that she had had a miscarriage and had gynaecological problems. She had read an article, she said, which reported the main problem areas for women were the throat, the neck and the genitals. This had struck her because she suffered from a sore throat and gynaecological problems since meeting John after the war. Orifices are seen as vulnerable; they are the regions where GWS enters.

One veteran told me he had passed on his illness both to his wife and to his stepdaughter. George told me that he had been diagnosed by the GVMAP in 1995 with the Epstein-Barr virus. This virus is commonly known as “the kissing disease”<sup>2</sup> and I soon realised that George had interpreted this in terms of a sexually transmitted disease. He explained that being told of his diagnosis was “not very pleasant”. He further said that the doctor had told him that he would have to “tell his missus” and that it was very difficult having to tell her. George said that his wife is now suffering from it as well as CFS. His stepdaughter, he informed me, had been diagnosed with CFS and that he understood that she had contracted it from him. I asked George how he thinks his family could have contracted the illness: “With the wife, some of it was sexual contact. Well, she has to go to the hospital for an appointment later on this month for vaginal infections. And the others, the ME, you know, chronic fatigue and that it’s obviously airborne.”

I asked George how he had made the link between his stepdaughter’s illness and the Gulf. He suggested that this had come about in 1994, “once I sort of realised I was ill, and I’d been in touch with the Nicholsons and they sort of said that there is a family connection, and things just fell into place”. Women are infected with their partner’s illness through contact with their semen and, in some cases, by mere proximity to the contaminated sufferer. In these narratives, sex and death take centre stage. The two most powerful notions and their symbolism are reversed: blood and semen are no longer the sources of life, but, instead, sources of illness and death (for a similar discussion about AIDS, see Wallman 1988).

### *Birth Defects: Children Contaminated through Men*

The most alarmist and upsetting media reports and stories about GWS have been about birth defects. Immediately after the war there were persistent rumours of birth defects and increased rates of miscarriages

2. It “was really after the discovery in 1968 of Epstein-Barr virus as the cause of mononucleosis that EBV became a disease of fashion, because the vast majority of the population bears EBV antibodies in the blood. Disproof was impossible. Finally ‘evidence’ was at hand that sufferers were ‘really ill’: Their blood tests (and everybody else’s) showed the antibodies. This particular proof seemed to be dramatically delivered in 1984, when an epidemic of still-inscrutable character occurred at Lake Tahoe. EBV antibodies were detected in blood samples of some of the victims, and the case for organicity seemed to be clinched” (Shorter 1992: 309). EBV has also been called “yuppie flu”.

among the families of returning veterans. Problems in reproduction take a predominant role in discussions of GWS and, indeed, are often the most discussed outcome of the war in the public arena. Once again it is semen that is implicated. Conception is seen as risky and full of potential problems. When conception does result in a child, veterans believe that birth defects are likely. At this point, however, it must be noted that although this belief is widespread in both veteran circles and the general population, there is no evidence that Gulf veterans have children with excess birth defects (Cowan et al. 1997; Araneta et al. 2000). Doyle et al. (2004, 2006) found no evidence for a link between paternal deployment to the Gulf War and increased risk of stillbirth, chromosomal malformations or congenital syndromes. Associations were found, however, between fathers' service in the Gulf War and increased risk of miscarriage and less well-defined malformations.

[For] male veterans there is no strong or consistent evidence to date for an effect of service in the first Gulf war on the risk of major, clearly defined, birth defects or stillbirth in offspring conceived after deployment. For miscarriage and infertility, there is some evidence of small increased risks associated with service, but the role of bias is likely to be strong. (Doyle et al. 2006: 571)

There was no evidence of an association between risk of miscarriage and mothers' service in the Gulf. Although two out of four reproductive health studies evaluated by the MRC review "showed an increased incidence of self-reported birth defects among Gulf veterans, their independent measures of birth defects found no association with Gulf service or reported exposure to particular hazards" (MRC 2003: 4). It must be remembered that 1 out of 40, or 5 per cent of births result in birth defects, and miscarriages rates are much higher than is commonly known. Despite evidence to the contrary, veterans remain convinced of the prevalence of birth defects and other problems in their reproduction; thus, this belief remains a central tenet of GWS.

Many veterans would tell me that there are high numbers of birth defects in children born to Gulf veterans. When I asked them how many they had met or knew of personally they would invariably say that they did not know of any personally, but had read about them or heard about them. The children of two veterans, Mark and Harry, are often cited as proof of the increased rates of birth defects. The following conversation with Paul is illustrative of this use of one or two cases as evidence of an overall occurrence. I asked Paul if he knew of any children born to Gulf veterans who had birth defects,



Yes, a lot. I know personally there's one. Harry, his son has brain damage. Other people have kids with deformed fingers and feet.<sup>3</sup> Webbed fingers and feet, autism, memory problems, behaviour problems, and problems with their joints. [How is passed on?] I think it's altered the reproduction systems. In the semen so it can carry. The Americans have had the same problems as well with deformities. They have the same problems as their parents. I think it's some sort of cells, some sort of way that's been passed on. Through blood, cells, semen or whatever has been passed on.

During our first meeting, Rebecca told me that men were twice as likely as the general population to have children with defects and women veterans were three times more likely. To illustrate this claim, Rebecca told me about a family where the father was ill with GWS and the four children had also been affected. This was Mark's family, introduced in Chapter 1. Debbie and Mark were very well known and had appeared many times in media reports. They were the "face" of GWS birth defects and have appeared in numerous media reports about GWS and its relationship with birth defects. It is possible that because of the high profile of these two families, veterans and others read the numerous stories in the media and interpret them as multiple stories. The information has the effect of multiplying the event. It would seem that people are creating theories out of the anecdotal evidence about a few cases.

When I first spoke to Debbie on the phone she told me that the children all have problems, but the eldest has the most serious disabilities. She said all of the children have deformed feet, asthma and bowel problems. The eldest, Michael, has language delay, deformed ears and feet, chronic fatigue, problems with food, and they were now investigating whether or not he has autism. When I met the family I was surprised to see that there appeared to be no signs of deformities in the children. When I inquired about this Debbie pointed out Michael's ears, which seemed mildly misshapen. She then pulled off the shoes and socks of the children to point out their "deformed" feet and toes. The children's feet appeared normal; the last toes were, however, slightly overlapped with the toe beside it. Debbie told me that the children's deformities were the same as those which were appearing in children in Iraq and that is how she knew it was something to do with the Gulf.

3. Although Paul did not directly suggest that he was speaking of Mark and Debbie's children, the common description in media reports and amongst GWS circles is that they have deformed fingers and toes.

Debbie explained that their doctor had told them that he had never seen anything like Michael's ears before, but he had told them that the problems with their toes were common. Debbie suggested, however, that to have both deformed ears and toes at the same time made it uncommon. Thus, to have one of the symptoms in isolation would have been acceptable, but it is the combination of symptoms that made it an issue. Debbie told me that the children have various and differing symptoms, but all the children have stomach and bowel problems.

I asked Debbie about what she thought had happened to her children, as she clearly thought they had birth defects. She said: "It must be something to do with the Gulf. No one else has four kids that are ill." Her husband Mark added, "I can accept having one child having problems, two maybe, but having four kids who are ill?" I then asked them if they knew other, non-veterans, who had children with birth defects. Debbie responded that they knew one child who had "a language delay, but Michael has that and physical problems. If it had just been the language delay I would not have associated it with the Gulf, but because language delay and toes et cetera and there is no history in the family of these things."

When I asked Debbie what she thought might have caused these problems in other families she said that she thought it must be down to family history. She said that genetics is the key to these things and that they had had Michael tested to see if he had the "gene which causes language delay in boys", but Debbie did not have the gene. Mark, the father, was not tested.

I later spoke to Mark's parents, the children's grandparents. They said that they felt having four children in the same family with problems was "too much of a coincidence" and that they had 14 grandchildren in total and none of the others had problems. They suggested that "should mean something" and further indicated that, "something, somewhere would have shown up." The grandmother said that she was also part of a big family and none of them have any problems and, thus, it "surely must be something to do with the Gulf". It is as though family history or genetics is the explanation people turn to in order to make sense of illness. When there is insufficient evidence of this, the Gulf is automatically implicated.

Semen is understood to play the central role in birth defects. Again, semen, viewed as the physical essence of masculinity, is seen as playing a chief role in contagion. During my interviews I would ask veterans if they thought the illness could be passed on to others. If they felt it could, which the majority of them did, I would ask how this might occur. Most veterans express uncertainty about the exact nature of this transmission, but commonly suggest that it is something carried in

semen. Sean's discussion below is representative of the kind of answers I received to the question of how transmission occurred.

Through my genes? If it was transmitted in any other way, like a communicable disease, then it would have affected the others as well and my wife. [So do you think possibly the exposures affected your genes?] Are we carrying around these chemicals in our body and you know, are they still there? Are they going into every sort of facet of our body? Sperm has blood and everything in it and your carrying other chemicals around in your body then that's creating a chemical imbalance or something like that. Who knows what it could be doing?

Semen is believed to contain the essence of the body and the man. Sperm, according to Sean, has "blood and everything in it" – it contains the nature of the man in minute form. Another veteran, Sara, expresses similar understanding of the role of semen in the transmission of the disease to children:

If something that's affected the nervous system and it's because of a drug or something, if they haven't been tested properly. These are lying maybe dormant or it's in your system you pass on to your children. Like a man who's a drug addict can pass on to a child. Or somebody with HIV can pass it on to a child. No one has said it's not like that. If you have GWS ... if it's because of uranium, that's for life, not just for Christmas. If you father a child and there's uranium in your semen then the child is going to have it.

Sara<sup>4</sup> suggests that her concerns about having "damaged" children were one reason why she and her husband had decided not to have children. She is concerned by the media reports of children with "problems with their kidneys and brain problems" being born to Gulf War veterans. Male veterans, however, are the ones who seem to be implicated in the illnesses of their children, according to Sara. She said that in the "Paper and on TV it's always been the father of the child announcing 'I was in the Gulf' ... I haven't heard of or seen of any women who say 'my baby was born deaf because I was in the Gulf'. But there is a tiny nagging doubt, one per cent, saying what if? You know, it's there."

Although Sara thinks that children born to Gulf veterans after the war may be at risk from illness, she does not think that it is contagious. "It's not something like, don't sit in the room with him: he's got GWS.

4. Sara suffers from migraines which she believes are attributed to her service in the Gulf, but otherwise considers herself healthy.

It's not HIV or AIDS or Ebola virus or something stupid like that that you can catch."

Interestingly, she does think it could be transmitted if it were a psychological or psychosomatic illness. This notion of the "contagion" of illnesses such as depression was repeated on numerous occasions by healthy Gulf veterans in their attempt to understand GWS.

Amongst healthy Gulf veterans the possibility of having children with birth defects seems to be an overriding concern. Thus, although they remain symptom-free and healthy, there is a concern that something remained in their body that could affect their children. James, a healthy Gulf veteran, said:

I can only be guided by the evidence. Whether it is GWS or something else, I don't know. I am fine. There possibly is something, but I am fine. But if I were to have a child who was born with birth defects then I would blame it on the Gulf. [Why is that?] Because there is no family history of anything like that either on my side or my wife's. The Gulf is the only thing I could blame it on [...] I suppose it could just happen. But there is something that I have in my past that would explain it. It's like if I found out I was infertile. I know I was fertile because I got a girl pregnant and she had an abortion. So if I found out I was infertile I would then investigate and come back to GWS and I think I would have the right to do so. [...] If it were a small heart defect I wouldn't blame it on the Gulf. I know these things happen. But Down's syndrome, I would blame on the Gulf. [Why? Do you not think that sometimes children are just born with Down's syndrome?] It is easy to say that anyone could have a Down's baby but I would find that hard to take.

During a follow-up interview I asked James to expand on what he had told me during our first meeting.

If I got cancer I would not blame it on Gulf. It would have to be something unusual. If I had a three-armed baby I would blame it on the Gulf. That's not a normal birth defect... Or if I were told I was infertile. It must be something because I wasn't infertile before [the Gulf War]. So it would point to the Gulf. But if they said 50 per cent of over 40s, and I am 40, become infertile I would believe it. I would not say it was GWS if I got cancer because that happens.

James' comments are common amongst non-sufferers and the general public. It is as though there are some situations which demand explanation and blame, and having a child with a birth defect is one such predicament.

The way the friendly fire incidents informed veterans' understanding of their illness was discussed in Chapter 4. Friendly fire metaphors are also used to describe the contamination of women and children through

their contact with men who fought in the Gulf (such as Ed's report of his sperm attacking his wife's egg). Lee suggests,

I was having mood swings, drinking. That progressed. My wife moved back to the UK with our daughter, who is eight. I had problems seeing my daughter. She has heart and lung problems. That was the main thing that got me on the Gulf War programme. I signed on the dotted line. I'm big enough and ugly enough to handle it, but my daughter ... that is like friendly fire and if I have another child ... I couldn't handle a disabled child. So I went for the test [GVMAP] in 1997. Came out feeling like a male rape victim. They didn't believe a single thing I felt. My dad was in the RAMC,<sup>5</sup> so I had faith in the army medical service. I told him that I had taken BATS and NAPS. And he said don't be so silly, nobody took BATS. 650 of my regiment took BATS. He accused me of being a liar. He was asking questions but not listening. If I was raped that is how I would expect to feel.

Lee explicitly states that birth defects in children as a result of exposures in the Gulf are "like friendly fire". He further explains his experience of going to the GVMAP as a kind of rape. The sexualised nature of his explanation is characteristic of veterans' discussions. Likening the situation to rape is possibly his way of expressing a feeling of being feminised.

In the same focus group mentioned above, John and Jack also discuss BSS and issues of contagion. They then turn to the impact on the Iraqi people as well as on their own family members:

*John:* We've committed genocide against the people of Iraq. But ah, history will right that.

*Jack:* There is a big hoo-ha about Chernobyl but there hasn't been a hoo-ha about all these people being deformed in Iraq. And indeed, to UK veterans.

...

*John:* Harry, who you saw today, both Jade and her brother Thomas, Thomas has severe brain damage. Jade has hearing and speech impediment and learning difficulties. Now you think about Mark's children all four of them. Harry, both of his, Mark's children.<sup>6</sup> Now, Mark's job was to remove the vehicles that were hit as a tank transporter. So he was undoubtedly exposed. Harry was a chef, so his regiment broke through and camped right in the middle, so he would have been jumping on tanks like the rest of them. They shouldn't have done it. They should have restricted the movement of troops after the war

5. Royal Army Medical Corps

6. Again, these two families are used as proof of the link between GWS and birth defects.

*Jack:* You've got many, many, many cases where wives and female veterans have actually lost children.

*John:* Yes, I mean, Rebecca and I lost a baby. But that's not the only occurrence. Some of the children born to veterans have been horrifically deformed. Which has been recently brought out by a paper in America ... [which] looks at health defects of children born to veterans in the Gulf and shows substantial birth defects in veterans children. And admittedly that group of soldiers would have been more exposed to DU anyway. But that's not the argument. The argument is that we've done it to ourselves.

John stresses the fact that “we’ve done it to ourselves”; it is their own government implicated in their illness and the illnesses of their children. In this case, John is specifically talking about depleted uranium. In the above quotation, John also discusses the effect of the war on the Iraqi people, particularly Iraqi children. Veterans say that the birth defects found in their children are the same as those found amongst Iraqi children born after the war. When veterans discuss birth defects they most often discuss them in relation to semen made toxic by way of exposure to depleted uranium.<sup>7</sup> The anxiety surrounding depleted uranium could be seen as rising out of a belief that it is a radioactive substance. It was a new weapon and thus mysterious to many soldiers who were not familiar with it. Discussions of DU and its relationship with birth defects are reminiscent of the post-Vietnam War anxiety about Agent Orange. Agent Orange was implicated in horrific birth defects in children born to Vietnam veterans and Vietnamese children. Fears about the effects of Agent Orange occurred during a more widespread anxiety about invisible chemicals and toxins. During this period there was widespread fear about DDT, which was thought to enter the food chain through plants and would, in turn, contaminate children. One of the most influential books of this period was *Silent Spring* (1962). In it, Carson, a biologist and writer suggested that pesticide sprays were “a kind of fallout”. She stated, “in this now universal contamination of the environment, chemicals are the sinister and little recognised partners of radiation in changing the very nature of the world – the very nature of life” (Carson in Wheelwright 1002: 177). Despite the widespread belief in the connection between Agent Orange and illnesses, including birth defects, the link has not been proven.

7. Doyle et al. (2006) cite a US General Accounting Office report in 1994 that identified 21 potential reproductive toxicants and teratogens that were present during the Gulf War (US GAO 1994). These included: arsenic, cadmium, mercury. Attention, however, tended to be focused on a much smaller range of exposures.

In a number of cases veterans extend discussions of exposure to DU. As mentioned in Chapter 4, exposure to DU, according to veterans, can occur indirectly. Veterans report that many of them brought back souvenirs of the war: visual reminders and proof of their participation in war. On a number of occasions veterans would suggest that these visible totems were implicated in the illnesses of family members and other innocent victims. One veteran, Brian, suggested, “we all have souvenirs. I have shells in the house and my kids have all these symptoms”. He said that he had four shells that he displayed in his house and that his children had become ill as a result.

Rebecca told me a theory about birth defects that I subsequently heard repeated on a number of occasions. Within the first three years after the Gulf War, health problems were indiscriminant with regard to a baby’s sex. Rebecca suggested that both male babies and female babies had birth defects and subsequent problems. The situation since 1997, she argued, was different in that only male children were at risk. Thus, Rebecca suggests that in the early years after the Gulf War all children were likely to be affected by their father’s participation in the Gulf. Now, only male children are born with birth defects due to GWS. As mentioned previously, I was told that Rebecca had had a miscarriage, but she had since given birth to a healthy girl. I asked Rebecca during our time together if she was worried about having children because of John’s GWS. She told me that she had been to some extent, but overcame this by thinking that it might be a girl. Rebecca also suggested that she knew if there was something wrong with the child she could choose to abort the fetus, as she “knew she couldn’t cope if the child had problems”. She told me she had a “good gene family” and that once she knew it was a girl she knew the child would be fine because it was mainly the boys who had problems.<sup>8</sup>

The notion that contagion is passed down through the male line was further described by Harry. Harry has two children, Jade and Thomas. I was told that Thomas has brain damage and, as Harry describes, “the right-hand side of his brain isn’t formed properly so he has learning difficulties and behavioural problems”. Thomas’ problems were further described by Harry: “When he was one we found his speech was not OK. It was a long struggle. They gave him a brain scan and they found that his right hand side is inside out.” Harry told me that Jade was fine.

8. It is possible that this theory (which I only heard mentioned by well-known association members) resulted out of the recognition that a number of well-known ill veterans had had healthy children, after media reports of birth defects. The two leaders of the association had had healthy children, both of whom were girls.

I found this interesting, as John had suggested that both children had birth defects (see above).

Below Harry describes how he understands his son's illness is related to his participation in the Gulf:

As I say my son, Thomas, has got brain damage [seen on] an early CT scan and ... what's now I'm thinking I may have passed it on genetically from the way I am. So that's the next thing we will be looking at is having a chromosome test for me and my son to see if there is any link. I mean, my daughter, Jade's OK and it's the male that passes it on to the son. So I think we just want to find out if there is a connection and if there is anything that can be done to improve his quality of life ... I think that as I've had that many vaccinations and that my immune system, my immune system has been messed up, really like. And Thomas is a Gulf War baby – he was conceived you know, not long after the Gulf War, you know. And he was a boy. A lot of other veterans who have children with the same problem they are all boys. So that's why the question is because they did actually did pass on via the cells the father's like.

I then asked Harry how it would be that male children were affected, but female children were not. He replied: "The theory is that it's the X gene [*sic*] in the chromosome through the male. That gets passed down to the boys. I don't know the scientific. It's something to do with the genetic build up, like."

Harry's discussion contains a number of different factors illustrative of illness models of GWS. He suggests that those children, such as Thomas, who were born soon after the war were more at risk than those who were born more recently, like Jade. Thomas is a "Gulf baby", defined by his father's participation in the Gulf. Veterans' bodies, immediately after the Gulf are more potent and hazardous and randomly affect their offspring. At first it would appear that in time veterans' bodies become less toxic, as those children born more recently are seen as less likely to be affected. Upon closer inspection, however, this is not the case. Instead, this theory suggests that the illness becomes concentrated in maleness. Men pass on maleness and masculinity to their male children and, thus, it is only male children that have the possibility of being damaged.

### **The Soldier's Body: The Embodiment of Masculinity**

GWS affected the very core of sufferers' masculinity. Indeed, it is through their masculinity that their wives, partners and offspring are affected. Veterans impart a strong notion of masculinity in their



discussions; these are deeply rooted in the body. Masculinity is almost always thought to proceed from men's bodies: to be inherent in a male body or to express something about a male body (Connell 1995). The ideal and normal state is one of ultimate fitness – a state stressed in the military. Any deviation from the muscular, fit body is seen as illness. Masculinity and the veterans' identity as a soldier were dependent upon their body and its ability to perform. This notion of masculinity is connected to strength and fitness, both externally and internally. These notions are linked with the previous discussion of body boundaries and the immune system. Strong, masculine bodies have strong, adapting immune systems and impenetrable defensive barriers.

One cannot stress enough the role of the military in defining masculinity. The forces are a masculinising institution and the organisational culture of armies is heavily gendered. Indeed, the military can be seen as the embodiment of a sexualised masculine ethic (Littlewood 2002). The body of the soldier can be seen as a kind of exemplary masculinity. As Connell suggests, violence "on the largest possible scale is the purpose of the military; and no arena has been more important for the definition of hegemonic masculinity in European/American culture ... The figure of the hero is central to the Western cultural imagery of the masculine" (1995: 213). The production of exemplary masculinities, like the soldier, is integral to the politics of hegemonic masculinities (Connell 1995). This symbolism of masculinity, however, is not fixed.

I was told that in the military the body is seen as a tool or as a weapon. Nigel, a healthy veteran, who was concerned about colleagues he felt were suffering from GWS but were ashamed to come forward, discussed at length the view of the body in military culture:

It was a strange culture, for example, if you were overweight, even if you are not overweight, I was a big lad and I used to have pie jokes thrown at me all the time and yet I never failed any test physically. I had a friend who passed SAS selection, came back to get his kit, and he was a little chubby lad and he was having jokes about being in the special pie squad from blokes who weren't half as fit as him. There were also racial things and ginger haired things. It's a very critical culture. It criticises everything in, I suppose, quite a bitchy way. And the body is part of that. Your physical and mental health has to be without blemish ... The worst thing to be known is to have not passed the BFT.<sup>9</sup> If you failed the physical test ... [you could be] classed as a wanker.

9. Basic Fitness Test. This test is the fundamental measure of fitness in the forces and must be passed by all recruits before they are accepted into the forces. All soldiers must also pass this test yearly.

Whilst explaining the culture of the military, Nigel talks about the way it is very focused on the body. Nigel's language is highly gendered and sexualised: he describes the culture as "bitchy" and explains that people who failed tests would be called "wankers". Being unfit or even looking unfit attracted ridicule. As he suggests, the "worst thing" is to fail the basic fitness test. Thus, one's integrity and masculinity is dependent upon easily observed fitness. Interestingly, the notion of "fitness" has been increasingly linked to attractiveness: to be an attractive man you must also be physically fit.<sup>10</sup>

Notions of masculinity are also linked with an absence of weakness and emotions. Indeed, it was very hard for veterans, they said, to approach people about their illness because soldiers do not go to the doctor or admit they are ill. I was told by both ill and healthy veterans that, "illness is seen as a bad thing in the army" and that "to report sick is taken as a form of weakness". This inability to accept illness is said to be a "male thing" and common in the military ethos. Henry, a high-ranking officer, emphasised the role of masculinity in service culture and the impact it has on the acceptance of psychological problems.

If you're a man (most are men and those are the ones I worked with for 34 years) and your manhood, your masculinity, your strength and your invulnerability are cornerstones of your placement in society. Whoever you are. And certainly if you strap military uniform on for many years, it's how we condition them. So we're all vulnerable to it ... I'm not a babe in arms, I think I would have been mortified to be diagnosed with PTSD ... Mortified. Because, again, either I think a lot of my self-esteem was based on the fact that I coped awfully well with combat. And enjoyed it and I enjoyed inspiring and leading through it. If that had been a part of the conclusion [of what was wrong with me] I'd have been gutted, I really would. So I think you can take shades of that right through the spectrum. "I'm one of the body, I can hack anything." When you come home, "you haven't been able to cope with stress." "What!" It unnerves them and it destabilises them itself.

## **GWS Bodies: The Disappearance of Masculinity**

Veterans valorise their pre-war identity and bodies by describing extreme masculinity and strength. Ben explains, "Before I went to the Gulf, as I said I was superfit ... You are superman." When veterans discuss their illness and their present state they say that they are

10. I owe this insight to Professor Danny Miller.

deteriorating, old before their time and weak. This weak state is held as a foil to their pre-war bodies and selves. Another veteran, Sean, says:

I really don't know what to think. But I definitely know I'm not well. I've always been a very fit, very active person. I used to do my training three times a day. Morning, noon and night, everyday, without fail. I was one of the fittest people ... Now I can't do bugger all, basically. I can't even lift weights anymore because it causes pain in my neck and my neck goes into spasm ... I've had to lose a lot of bulk through inactivity.<sup>11</sup> And again, when you don't exercise and you don't release endorphins so it doesn't help the depression side. I know I'm not as tolerant as I was with people and things ... [A]t first I was paranoid because I thought I'm falling to pieces here, why? I've gone from a person, I liked me; I was full of myself because I can do the things I can do. I was proud of my body, I was proud of my athletic prowess. I was proud of the fact that people didn't tell me what to do and I could hold my own in any argument: mentally and physically. And then all of a sudden I started despising myself because I was like an old cripple. My mind wasn't working right, my body wasn't working right, and I was turning into an old man. I felt I was dying from the inside. It wasn't affecting me, it was affecting everybody. My family and friends.

Masculinity is also linked with work and the job of a soldier. Being a man is also about providing for one's family. Previously, Harry described his understanding of how his male child was affected by his participation in the Gulf through his semen. After this discussion I asked Harry to describe to me how he felt physically. He replied:

Nowadays, I just feel, I don't feel how I used to be. I could manage things better. I can't work although I keep trying, like. I get tired easily. And it's role reversal at home. My wife works now and I'm doing the chores and that takes some getting used to, like. Because generally with all these health problems my skin, my sleep apnoea and my asthma and all these things wrong with me and that's how I am these days, a bit of a worrier, like. I think it's the fear of the unknown that's the worse thing, like.... I've had to change my lifestyle. I'm a househusband and that. It takes some getting used to but you have to know your limitations. And I know my limitations I can't do DIY and that.... I have to admit that at first I felt a bit inadequate. But then I thought to myself, and I've had counselling...that having a home and family is important in itself, like. And I've learned through these counselling sessions that if my wife was ill and I was working it wouldn't be a problems... you've just got to adapt to what's best for you.

11. Sean is suggesting that he had to lose a lot of muscle through not being able to exercise and lift weights, thus, changing the appearance of his body.

Harry's comments reflect the view that men are seen as the "breadwinners." In the army their body was their means of survival, in the absence of the army what role does their body play? Is it redundant? Through their illness, or prior to their illness through leaving the forces, this expression of masculinity was taken away from them. Masculinity is linked to work. Most of the Gulf War sufferers I spoke to did not work and depended on the pensions and benefits they received as a result of being an ill veteran. Many of their female partners worked and ran the home. In their discussions about their illness, veterans stressed their inability to work and that their partners saw "a fit man becoming ill and losing jobs." Thus, they had gone from having a heightened male identity: being a soldier, a war veteran, and a worker to being what Harry refers to as a "househusband." Importantly, he also admits that he is unable to undertake carry out DIY, something which is commonly seen as a masculine pursuit.

Veterans themselves and their advocates paint very emotive pictures of their bodies. During the US congressional hearing at the House of Lords, the comparison of pre-war masculinity and fitness to post-war was the focus of the presentations. A US Congressman said:

They were exposed to a host of toxins. They were vibrant, potent, strong and came back broken, battered and suffering. They came back with old women's diseases. Diseases of the old. The plight is real and it is physical.<sup>12</sup>

Ross Perot then said of the Gulf veterans that he had seen:

They were Captain America. They brought in pictures of themselves. They were muscle men and now they looked like people coming out of Dachau in WWII. And brought pictures of their children with severe birth defects. I am not a doctor. I have been accused of being one but I can see this is not stress. This is about how we can protect our armed forces and our entire population from terrorist activity.<sup>13</sup>

Veterans' bodies are described as once masculine and ideal: "Captain America". This masculine ideal of fitness and strength is now lacking in their bodies: they are old, weak and in need of help. They were "potent," they are now dependent and "broken". Once again we can see the way that discussions about GWS are, in many ways, not solely about the Gulf War. Instead, it is a vehicle for talking about other

12. This is not a direct quote as it is based on notes I took during the meeting.

13. Also not direct quote as not taped interview.

things, in this case a platform for US politicians to discuss terrorism and widespread vulnerability. GWS expands outwards (see Conclusion) it brings together disparate anxieties of our contemporary context.

Many veterans report that they found the final period of their time in the forces difficult because they were unable to maintain fitness levels, the cornerstone of masculinity in the forces. Thus, their bodies were failing them and not living up to the ideal male soldierly body. Linked to this inability to cope is the notion of fatigue. As mentioned above, the military body is one that is strong and has endurance, it does not tire; yet GWS sufferers most common complaint is fatigue, their bodies are in a constant state of lassitude. Such a notion of fatigue seems entwined with notions of aging, weakening and losing potency. In the forces fatigue is seen as entirely negative and is given feminine connotations. This is made all the more symbolic with the entrance of women into the forces and the subsequent advent of different criteria of endurance for female soldiers, something that will be discussed in the next chapter.

### **“Old Women’s Diseases”**

As we have seen above, GWS narratives emphasise the toxicity of semen and in many ways, the toxicity of manhood itself. The men talk about being transformed, changed by their time in the Gulf. This change, however, is seen almost entirely in physical terms. This change subsequently infects and harms their wives, lovers and children. They are fractured heroes, broken men and the essence of being a man- their semen- is equally damaged. This transformation of male identity and personhood is further expanded by veterans’ discussions of the illnesses from which they suffer. Veterans and their advocates constantly told me that they suffer from “old people’s diseases” and “old women’s diseases.”

They suffer diseases of women, further emphasising their de-masculinisation. This description of their bodies is held in stark contrast to the way they describe their pre-war bodies as muscular, fit, and strong. During an early interview, Rebecca told me that veterans’ bodies “just don’t work well”. She said they are either too fat or too skinny because their bodies do not work properly. She also said that there are higher rates of anorexia in male veterans, “which is just not common normally”. Rebecca then used a well-known veteran to illustrate what she was saying, thus, the male bodies of veterans are not ideal masculine bodies.

Malcolm Hooper would often stress the fact that veterans' illnesses are "female" illnesses. "This is a disease mainly of women [Irritable Bowel Syndrome] and many things in Gulf cases are found which are mainly of women. Lupus, fibromyalgia, osteoporosis."<sup>14</sup> Veterans themselves point out the link between their conditions and female maladies. Describing fibromyalgia, one of his many symptoms, Mark said: "It is tenderness around the joints. It's more predominant in women than men until Gulf vets. It's rarely found in men or only in men who are older with really thick notes [i.e. with a complicated medical history]."

Tony, the sceptical veteran described in the previous chapter, discusses his experience of going to the AGM:

The guys with osteoporosis, that got to me a bit. Because that's an old woman's disease, sitting around too much. But these guys are active, young men and they are crippled by and old woman's disease. And that did disturb me. But as I say, I was more caught up in the euphoria of being there, rather than being convinced that I was one of them.

Paul, who walks with a walking stick, told me that he uses a walking stick because of his fibromyalgia and the pain it causes:

[I] was just diagnosed with osteo-arthritis just two months ago and with bones sticking out. I know people who were younger. I'm only 38. I know men as young as 25 have been diagnosed with osteoporosis which is brittle bones which is a lady's thing. Or you get it later in life. Or they are old people who were boxers.

Veterans often say that their illnesses are rare, or that to have the combination of various things is unusual. They also stress that when they do get known and common illnesses they get them at a younger age than normal. Chris, for example, diagnosed with MS, tries to make sense of this illness:

How come all of us at the age of 52 and 53? To get MS is most rare indeed, they say. Then period of mood swings. Fine one minute, raging temper next, loss of balance ... Asked to go for an interview and put me into body scan and requested my wife and I to attend to be told we've diagnosed with MS. They said it was very unusual in men of your age and in white people. It's usually in women, younger people and that's where we started. I had been developing over a couple of years ... Yes, became impotent and I would bite

14. Not direct quote as based on notes during a meeting.

my wife's head off. It is a build up of various things. At least they have given it a name. Whether it is MS ... My opinion when I went to the MAP. Professor Lee, he told me that pregnant women have greater exposure to the chemicals, so why would it affect you?<sup>15</sup> I thought, "thank you very much".

Chris reveals that he believes that his MS is rare because he is older, white and male. As he does not fit the criteria of those who normally are diagnosed with MS, he thinks that his illness is not "natural" and thus must be due to some unusual factor: the Gulf War. He repeatedly referred to his illness as "so-called MS" as though it was not true MS, but GWS which presented like MS. During my fieldwork there was increased interest in Motor-Neuron Disease (MND) and its relation to GWS. This was a result of the US accepting MND as related to service in the Gulf and one very public case of MND in the UK. Time and again I was told that MND was prevalent in Gulf veterans and that it was an "old person's disease". Interestingly, these initial reports were dismissed by the biomedical community. More recent studies have supported the reported elevated rates of MND, suggesting that it is the only disease-based outcome. However, as mentioned in Chapter 1, these findings have not been fully accepted by the biomedical community and they suggest this connection should be met with caution.

We can see that veterans interpret the illnesses from which they suffer as disorders of women and the old. In describing their illnesses as such veterans are describing their bodies as deteriorating and not ideal. During a casual discussion with John and Rebecca, John told me that all Gulf War sufferers have fibromyalgia and osteoporosis and that these are "women's diseases". Rebecca then said: "I think they are all turning into women. It's doing something to the male gene and the men pass on their male gene". This comment was vividly illustrated by Bob (see transcript at the beginning of this chapter) when he described what he called his "bitch tits". Bob sees his body as transforming and gaining female attributes.

15. My interpretation of what Barry is reporting here arises out of my time observing assessments at the MAP. When the doctor explained NAP5 tablets to veterans, he always showed them the description of PB in the drugs manual. He would point out that they were given far less than one is able to give those suffering from myasthenia gravis. He would also explain that the drug is so harmless that women who are pregnant are advised to continue taking the medication throughout their pregnancy. I think this is what Barry is referring to.

## Women

In this chapter I focused on men and masculinity, only discussing women in their relations to men, but what of those women who themselves were in the war? During my fieldwork I had eight female veteran informants, five of whom believed they were suffering from GWS. Their stories are remarkably similar to the men's narratives of GWS. Female sufferers focus on the centrality of fitness and the way their illness was an absence of this. They describe their pre-war/pre-illness bodies as those in a state of extreme fitness compared to now feeling old before their time and weak. They illustrated this in terms of lack of fitness, as did the men. The symptoms are generally the same. My findings reflect those of Unwin et al. (2002) who found that women had similar rates of ill health as men and with no gender differences for the majority of symptoms.

In discussions of masculinity and military culture we cannot ignore women or set them aside. Masculinity is a social construct and, thus, women can be considered as embodying masculine ideals as much as men. Women who join the military could be seen as likely to embrace dominant notions of masculinity. Women themselves can also be seen to eschew dominant notions of femininity, by adopting and valorising masculine mannerisms, behaviour and dress in their attempt to "make it" in a hegemonically masculine environment (Agostino 1997).

There were issues which directly related to women soldiers. I was told that women were put on the birth control pill so that they would not get periods in their suits. I was also told on one occasion, by a healthy woman veteran, that she understood that they did this so that any women that were captured would not produce a child as a result of rape. Female and male veterans reported that the side-effects women experienced as a result of the preventative measures taken involved disruption to their periods. Some told me that women's periods stopped or "went haywire".

George describes what he heard were the effects of NAPS tablets:

Well, good example, to show you how the NAPS tablets are, in my unit out in the Gulf, 205 general hospital, umm one of their nurses, you can appreciate this more than I can. After we'd been out there just over two months or so and taken the NAPS tablets, she was told by the doctors out there to stop taking them because she had her period for a solid two months. After loads and loads of tests, that's what they boiled it down to. Obviously, as a woman, you can appreciate that that's not very nice [laughs] and all the time we was out there we were having side-effects from the NAPS anyway; mainly diarrhoea.



Rumours also abounded about the effect of exposures on reproduction. One healthy woman veteran told me that the woman with whom she had shared a tent in the Gulf had been advised not to have children for at least one year. None of the women soldiers I interviewed had had children after the war nor reported problems with reproduction. Interestingly, all the ill female veterans I met were single: two were divorced and three remained single.

## Conclusions

As we have seen in Chapter 3, for veterans there is anxiety about substances that traverse the boundaries of the body, semen being the most profound of these. During my fieldwork I was struck by how central issues of semen and reproduction were to veterans' discussions. I became convinced that there was something important being conveyed. Why semen? Why do they talk about it so much? Semen breaks body boundaries to the extreme. Semen has potential. It is what makes you a man and you are able to transfer that to others.

When a society is under threat it is often women's bodies, and predominantly orifices, that are seen as vulnerable and in need of protection (Boddy 1989). Anxiety about semen suggests that men's bodies also map vulnerabilities of society. Concerns about lack of potency, toxicity and quality suggest that semen itself is a substance in which social concerns are enacted. As Douglas suggests, the fluids of the body turn out to be a kind of language in which various themes find their voice (1966). Semen is powerful and the exchange of semen full of meaning. Anthropologists have focused on the meaning behind semen. For example, among the Sambia in New Guinea men are apprehensive about being depleted of their "limited supply" of semen, which they equate with mother's milk (Herdt 1981). Dhat syndrome, a South Asian illness, involves the preoccupation with loss of semen; there is a fear that semen is being lost, and mixed in urine. Seen most frequently amongst young men at medical and psychiatric clinics in South Asian countries, the common symptoms of the condition include fatigue, weakness, palpitations and sleeplessness (Jadhav 2007).

Anxiety about semen in the Euro-American context is not unique to GWS and has been investigated by others (Jadhav 2007; Reynolds 2007; Shand 2007). Indeed, Galen and Aristotle drew attention to semen as a "soul substance" and outlined the debilitating consequence of semen loss. Jadhav (2006) has argued against a reading of dhat as culturally bound because there is sufficient evidence to confirm prevailing concerns over losing or retaining semen in Euro-American

societies. Furthermore, Jadhav's work suggests that there may be a link between depression and anxiety about semen loss. Narratives of GWS focus on semen and an ambivalence about the potency of this substance. On the one hand their semen is seen as impotent, characterised by low libido and infertility, yet on the other hand discussions of burning semen syndrome and birth defects suggest their semen is overtly potent, destructive and often hostile. This relates to their descriptions of being violent, irritable and aggressive.

The military could be seen as the embodiment of masculinity – a masculinity under threat, however, as will be discussed in the next chapter. Soldiers can be seen as the ideal, exemplary male. The military moulds them through constant exercise, hair cuts and uniforms to become the picture of masculinity.<sup>16</sup> Semen is often seen as the seat of selfhood: the location of the self in biological form. It is not surprising in a culture such as the military, which characterises itself as ultimately masculine, that semen would be seen as central to notions of identity. I would suggest that when veterans are discussing their damaged bodies and their damaged semen they are, in fact, embodying their damaged masculinity. When veterans discuss lack of libido and impotency they are talking about a lack of potency and a lack of the sexual force of masculinity. Indeed, the very word impotency is a synonym for emasculation. Masculinity is integrally linked to sex and the ejaculation of semen, as we have seen above. Yet veterans express an inability to embody this masculine emblem. In contrast, they also suffer from a toxic and potent masculinity. They themselves are toxic. When veterans talk about the fact that only male children are now affected, they seem to be suggesting that maleness is transmitted biologically. Since their masculinity is somehow marred, veterans have damaged male children. Masculinity is the social elaboration of the biological function of fatherhood (Connell 1995) and once again the veterans come up lacking. Anxiety about impotency and potency of semen does not seem to be isolated to discussions of GWS but is instead characteristic of a cultural process. GWS, however, uniquely concentrates this issue of loss of masculinity.

16. US marines, the pinnacle of military masculinity, focus on creating bulk and muscle. Such a physique is not a requirement for their job. Indeed, it may be to their detriment as it impedes speed and endurance. However, the process of maintaining a body builder body is part of the image of the US marine.

## Chapter 7

# **IMPOTENT WARRIORS: THE CONTEXT OF NARRATIVES OF LOST MASCULINITY**

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The context and causes of GWS must be seen as wider than the Gulf War, as many other things were happening in the lives of these men. GWS was their way of making their various experiences intelligible. GWS shares certain features with other new illnesses, but it arises out of anxieties particularly relevant to a specific group of people: the package for these men (and women) is unique. GWS responded to, addressed and commented upon issues relevant to the specific things that were happening economically, physically and culturally in their lives. In this chapter I will provide an account of the context of GWS mainly through analysis of literature considering the war itself, militaries more generally, and the relationship of these to masculinity. This examination of the context will, I hope, shed light on the narratives discussed in the previous two chapters. In this chapter I extend my interpretation, developed in the previous chapter, that GWS is in part an expression of gender anxiety in the face of a changing military.

As we have seen, two of the unique aspects of GWS are its contagious nature and its focus on the loss of masculinity. GWS is believed to be passed on to partners via sexual contact and transmitted to others through different means. GWS narratives emphasise the toxicity of semen and, in many ways, the toxicity of manhood itself. Veterans, through their time in the Gulf, are altered and damaged. They subsequently infect their wives, lovers and children through their

bodies. They are broken men, impotent warriors. The essence of being a man – semen – is defective. Their bodies have transformed from the epitome of militarised masculinity to embodying a lack of virility and manliness.

## **Military Masculinity**

The military, populated primarily with men, plays a primary role in shaping images of masculinity in the larger society (Connell 1992; Morgan 1994). Military masculinity places great emphasis on stamina and physical vigour, and exerts extreme pressure on soldiers to live up to these ideals. Fienman (1995) argued that the media framed the Gulf War as a “rebirth of masculinity” following Vietnam, despite the relatively large number of female soldiers. Media coverage of the Gulf War made abundantly clear how pivotal the discourse of war is to the consolidation of the penis–phallus equation: conventional masculinity (Silverman 1992). Although “women are among the veterans, the war itself and soldier life in general have been culturally coded as masculine” (Shriver et al. 2002a: 132).

Militaries around the world have defined the soldier as an embodiment of traditional male sex role behaviours (Barrett 1996). Masculinity has long been associated with strength, toughness and vigour, while sickness has been coded as weak and feminine (Ehrenreich and English 1978). Just as militaries embody masculine ideals from culture at large, they also impact the notion of masculinity in the wider society. Consequently, the military and war are said to be sites where hegemonic masculinity is reproduced and maintained. The term “hegemonic masculinity” refers to a particular idealised image of masculinity in relation to which images of femininity and other masculinities are marginalised and subordinated. The hegemonic ideal of masculinity in current Western culture is a man who is independent, risk-taking, aggressive, heterosexual and rational (Connell 1995).

The link between masculinity, the body of the soldier and the ability to fight effectively has, at times, been direct. Bourke reports that in the First and Second World Wars there was a focus on the selection of the most effective combat soldier based on a “brief inspection of the body build to determine characteristics of masculinity” (1999: 111). Thus, combativeness was inscribed on the male physique. For soldiers their body is their tool, weapon and livelihood and that body must be a masculine body. Violence is turned on one’s own body and the body is virtually assaulted in the name of masculinity and achievement (Connell 1995). Furthermore, the individual body, its strength and its

masculinity stand for the strength and masculinity of the society as a whole.

One of my informants, mentioned earlier, differed dramatically from the others. He was a high-ranking officer and was ill with a chronic fatigue condition he did not attribute to GWS. Henry was also different in that he saw the mind and body as indivisible and related GWS to stress. He commented on the physicality of his troops:

One of the first groups of my [men]... who went downhill psychologically was a huge surprise to me. It wasn't the lounge lizards, the big boozers from way back and the degenerates; it was the barbell pumping biceps revellers. And I know why they went downhill first. Because they were losing their drip feed of endorphins or self-esteem or reassurance that came with their posturing and sweating twice a day everyday. It all had to go. They were in long watches tucked in the bowels and their bodies were going to hell. And they hated it. Those guys were actually showing us that the military's huge focus on physical excellence is actually a double-edged sword. So much of what we have to do is based on physicality. You can become wow and when you can no longer wow about your rippling body you say, Christ, I'm a heap.

Masculinity as warrior is central to the understanding of military cultures. Mosse (1990; 1996) has shown that although the notion of the warrior male had existed before, the First World War strengthened this connection. Moreover this "reading of masculinity as warrior involves a clear distinction between the protectors and protected, soldiers and civilians, warmongers and peacelovers, and masculinity and femininity" (Agostino 1998: 58). From "small rituals such as shaving heads and discarding civilian clothes for uniforms, to warrior initiation rites, violent drill instructors, hazing rituals, sex education films on the harms of venereal disease, recruits learn that there is 'a cult of toughness and masculinity traditionally associated with making soldiers out of civilians'" (Barrett 1996: 131).

Masculinity achieves meaning within patterns of difference.

[If] success for men is associated with "not quitting" in the face of hardships, femininity becomes associated with quitting, complaining, and weakness. This follows Kimmel's (1994) notion that definitions of masculinity depend on changing definitions of women and gay men who serve as the "others" against which heterosexual men construct and project an identity. In fact, there is a tradition in the military of reserving the labels associated with femininity for the "other" (Enloe 1990; Strange 1983). (Barrett 1996: 133)

In his study of notions of masculinity and the US Navy, Barrett found that from the first day of training, recruits who complained or did not keep up with the others were the targets of gendered insults: they were called girls, pussies, weenies and wimps by the instructors. Often while marching, the instructor leads the men in songs that demean women as weak and feeble (Barrett 1996). Thus, masculinity in the military sets itself up by associating negative traits with women.

Morgan writes:

Of all the sites where masculinities are constructed, reproduced, and deployed, those associated with the war and the military are some of the most direct. Despite far-reaching political, social, and technological changes, the warrior still seems to be a key symbol of masculinity [...] Traditionally, then, combat and military experience separate men from women while binding men to men. It is a separation which reaches deep into a man's sense of identity and self. (1994: 165–66).

Images and discourses of masculinity as warrior require as much as possible a negation of the feminine and homosexuality. One of the necessary “characteristics of masculinity as warrior is that of men's flight from the feminine. Most of this is done in response to a culture where men support and encourage one another's masculinity to maintain a hegemonically masculine culture” (Agostino 1998: 64). In relation to this Kimmel writes: “being a man means ‘not being like women’. This notion of anti-femininity lies at the heart of contemporary and historical conceptions of manhood, so that masculinity is defined more by what one is not, rather than who one is” (1994: 126).

Narratives about GWS go to the very heart of notions of masculinity. Veterans stress the physical notion of masculinity: masculine bodies are strong, muscular, fit and have effective, adaptive immune systems and impenetrable defensive barriers. Veterans commonly describe themselves and their pre-war bodies as the epitome of masculinity. In contrast, they depict their present state in terms of deterioration: old before their time and weak. The symptoms they most often discuss are fatigue, memory loss, aches and pains, and low libido – all of which can be associated with aging, degeneration, fatigue, weakness. Sexuality and sexual performance are an essential part of masculine identity; failure in this regard is most damaging to a man's sense of self-esteem.

Veterans often suggest that the first sign of their illness was a lack of fitness, often indicated through failure at fitness tests. Barrett found that the image of masculinity that is “perpetuated involves physical toughness, the endurance of hardships, aggressiveness, a rugged heterosexuality, unemotional logic, and a refusal to complain” (1996:

131). It is never assumed that such character traits are permanent, however. It must be continually confirmed and exhibited. Barrett points out that the Navy creates structures and routines that call for continual testing of these qualities. This “is a culture that chronically creates trials that separate the ‘weak’ from the rest. From the first day of training, the culture creates a testing ground that creates boundaries of inclusion around those who exhibit strength, endurance and competence” (Barrett 1996: 131). Men’s masculinity, then, is insecure and constantly in question. This follows Collinson’s conclusion that a culture that encourages continual comparison “recreates the social insecurity it is intended to transcend” (1992: 97). Many veterans told me that the worst, most embarrassing thing that could happen would be to fail a fitness test, with its accompanying insults of being referred to as women and homosexuals.

The physical nature of masculinity has been emphasised in military culture and the wider society. This relates to the fact that self and identity have been increasingly associated with the body (Chapter 3, 4 and 6). Mosse argues that the body itself took on symbolic meaning in the second half of the eighteenth century due to the fact that it was a more visual age; this affected notions of masculinity. For soldiers, “their outward appearance was crucial: supple, lean, muscular bodies, striking eyes” (1996: 115). Historically, combat effectiveness and characteristics important in war, such as valour, were found through physical inspection (Bourke 1999). Prior to and during the First World War the grading of recruits into categories “was based as much on perceptions of the relationship between physical masculinity and combativeness as it was on medical principles of healthiness” (Bourke 1999: 109).

Shriver et al. (2002a) have suggested that there were a number of cultural constraints to US veterans labelling their illness as GWS: their continuing patriotism, their value of group cohesion and an idealisation of strength and vigour. The latter was related to the association of military pursuits and health with masculinity. I would argue, however, that instead of constraining labelling illness as GWS, the idealisation of masculinity as strength and vigour might have encouraged perceptions of their suffering as GWS. Men who focus on fitness and health as the markers of masculinity may find it harder to accept their body’s inevitable decline. They may be more likely to need a reason for physical degeneration and failure. They are also more likely to focus on such decline and see it as negative and strongly unfavourable. Thus, they would look towards an acceptable reason for their weakness. One which points to their wartime experience, such as GWS, would be highly ideal. If sickness and inability to cope are coded

as weak and feminine, then these men would need a culturally acceptable reason for their state.

## **Masculinity under Threat**

Veterans are unmanned. As soldiers they were part of a culture which is the quintessence of masculinity; yet they now see themselves and their bodies as lacking this masculinity. I argue that it is a masculinity under threat. GWS emerged at a time when there were a number of changes in the lives of these men and in the military in general and, indeed, the Gulf War can be seen as a turning point between militarities and masculinity. During the period when GWS emerged the military was experiencing two major trends: “Options for Change”, and the integration of women. The phenomenon of “Options for Change” has appeared in the lives of the men I describe. This episode of the military’s history was one which had enormous repercussions for GWS sufferers. Prior to the Gulf War there was a concerted effort on the part of the government to trim down the forces. This meant redundancies as well as offering certain military jobs to civilian contractors. When hostilities developed in Iraq this action was postponed until after the war; however, once the war was over the MoD quickly resumed the process of reducing and altering the services. This meant that many soldiers, soon after returning from war, were faced with the prospect of redundancy.

Many of my informants report they were forced to accept voluntary redundancies, others say they were effectively pushed out and still others suggest that they happily accepted the offer of voluntary redundancy and the benefits that accompanied it. So, many of my informants along with other members of the armed forces found themselves stripped of their soldier identity and confronting life in the civilian world. “Options for Change” and the entrance of women threatened the dominance of the military man. The latter trend<sup>1</sup> created a challenge to the image of the male warrior. If these gruelling tests are there to separate men from the boys, what does it mean if women can pass them (Barrett 1996)? These changes also meant that soldiers were competing for fewer places and competition became fiercer. “Options for Change” and the entrance of women into the forces opened boundaries which had once been firmly closed to women and civilians.

1. “Options for Change” also brought about a threat to the male warrior identity in that many jobs became open to civilians.



Masculinity is defined more by what one is not, than who one is (Kimmel 1994). In relation to war, masculinity and femininity are set apart as polar opposites. Women's presence in contemporary militaries has precipitated some of the most vociferous essentialist arguments surrounding gender. The increase of women's participation in Western militaries problematises the hitherto exclusive link between masculinity and war (Morgan 1994). During the Vietnam War female combatants came to epitomise all that was emasculating about women in war (Bourke 1999). In America, the proportion of women in the US military increased from less than 2 per cent in the first two years of the 1970s, to nearly 5 per cent by the middle of the decade, and 7 per cent by 1990. In Britain, 10 per cent of the forces were female by the end of the 1980s (Bourke 1999).

Women were not seen to have participated in war as warriors prior to the Gulf conflict. In her interviews with Australian Navy officers, Agostino (1998) found that some men felt threatened by women they perceived to be actively competing with them for this warrior identity. A young Sub-Lieutenant, for instance, argued that during the Gulf War women were receiving "all" the media attention. In demanding equal participation with Navy men, women were "seen to be chipping away at this 'innate' masculine role. In doing so, men perceive women to be undermining the very fabric of society, to be going against 'natural' gender laws which endow each human with an essential sexual and gender identity" (Agostino 1998: 61).

At the same time as the changes outlined above more subtle changes were taking place which were changing the military in which Gulf veterans had served. The relationship between militarism and masculinity has begun to change (de Groot 1999), as reflected in the change in the military role in the postmodern world (Higate and Hopton 2005). Increasingly, the British forces were finding themselves in peacekeeping roles, often with limited power to act. Higate and Hopton highlight the importance of a 1990s British Army recruiting advertisement which "emphasised the intergration of women in the Armed Forces and, significantly, linked this to the growth in the army's peacekeeping role (2005: 442). It is apparent that "pure fighting functions will become of secondary importance" and that the main task for the military is now to "protect, help and save" (Dandeker 1999: 60).

The veterans I spoke to often described what they saw as the changing face of the military as a result of human rights laws. These laws meant there were stricter rules referring to how new recruits and others could be treated. Many cite this change as affecting the discipline within the armed forces. It was suggested to me on numerous occasions that such laws in effect weakened soldiers because physical discipline

and force could no longer be used; thus, the forces were undermined and weakened by these new changes. As has been discussed in previous chapters, the training of new recruits can be seen as a “toughening up” process or even “making men out of boys”. The new human rights laws, however, are seen to prevent this necessary process, meaning that the forces as a whole became soft and feminised. As Higate and Hopton note that within the UK military there was,

decreasing tolerance of physical brutality directed toward military recruits by their training instructors. If physical brutality were to be considered an accepted and previously unquestioned component of (military) masculine ideology, then changes to basic army training through which recruits are more ‘empowered’ (rendering them less open to physical and mental assault from instructors) represents a further important development (Dandeker 1999: 36; Skaine 1999: 138). (2005: 440).

Some military commentators have noted an eroding of firm boundaries around militaries as a result of a culture of rights and litigation. Fundamental to the system of war is the “recognition that soldiers are not merely civilians in uniform: they form a distinctive group within our society that needs a different set of moral values in order to succeed in circumstances which greatly differ from those prevailing in civilian life” (Rose 1997: 20). Furthermore, this military commander points out that this separation is necessary for, no other group in society is required to kill or sacrifice their lives for the nation. With the military following wider cultural trends of pursuit of individual rights, the division between civilian and soldier is further diminished.

Another change that occurred during the time most of my informants were in the military was the increased domination of technology. Success in war is scored mainly in terms of territory captured, enemy weapons destroyed or industrial infrastructure disabled (Clausewitz 1976; Payne and Gray 1980 in Gusterson 1991). Gusterson argues that the representation of the Gulf War was remarkable “for the way in which it treated bodies as objects for mechanical enhancement, weapons as surrogates for the bodies of warriors” (1991: 49). He also notes the absence in the media of maimed, scarred and dead bodies in a war that was entirely televised and had at least 100,000 casualties. Technology reigned supreme with supremacy portrayed in terms of the allies’ ability to transcend the limitations of the human body (Gusterson 1991). The body was re-engineered through machinery and medications, creating a more powerful and effective fighting tool. In focusing on the way in which human bodies could be improved, the vulnerability and deficiency of

human bodies was emphasised. The fit, strong, human, male body was simply not good enough.

The vulnerability of bodies to the threat of chemical and biological weapons was addressed with chemical protection suits, inoculations and NAPS tablets, which supposedly armoured ordinarily fragile human bodies against such threats. In order to suppress the body rhythms which constrained their Iraqi enemies, US pilots used amphetamines to enable them to bomb continuously. US and UK soldiers used night vision goggles and thermal sights to enable them to see targets in the dark which would not usually be visible to the human eye (Schmitt 1991). The bodies of the soldiers “thus had a post-human, cyborg-like quality<sup>2</sup> which was often foregrounded in television images of soldiers in chemical suits with masks, or in night-vision goggles” (Gusterson 1991: 49).

As Gusterson comments, the media representation of the war focused on the machinery involved. This often had the effect of making the war look like it was fought only between machines. In the postmodern age of war where bodies are deemed lacking and technology reigns supreme, is GWS an act of protest? Are GWS sufferers, through their symptoms and their suffering, demanding that their bodies be seen and heard? The body is crying out to be noticed. The question remains: what happens to these bodies when they are once again stripped bare? Bodies that were made to feel vulnerable and inadequate were hybridised, but after the war their machine and chemical improvements were stripped from them leaving them exposed: exposed and more aware than ever of their vulnerability. They are no longer a hybrid, superman or superhuman. Alternatively, the chemicals and medication given to them to respond to their vulnerability are now, as they see it, permanently a part of them: changing them and their bodies irreversibly.

The link between masculinity and domination of technology has a long history in militaries. Pilots have long been seen as the ultimate masculine ideal, a perception that began in the First World War. That “pilots controlled the most up-to-date machinery no doubt reinforced the masculine ideal [...] The fighter pilot mediated between the individual and the perils of modernity” (Mosse 1996: 118). Thus, those who do not master technology or, worse, are mastered by it, are deemed less masculine.

2. It has been argued that gender is blurred in the cyborg soldier (Hables-Gray 1997). Technological developments in a postmodern world could be seen as moving towards a situation where women soldiers are interchangeable with male soldiers (Higate and Hopton 2005).

The changes mentioned above directly affect the lives of these men and the way they experience the world. The majority of the veterans I met had taken (or been forced to take) redundancy during the period of “Options for Change”. Thus, within months or a few years of the Gulf War they were made redundant; they lost the military identity they valued so highly. Most suggested that they found the change from military to civilian life difficult – that they simply could not fit into civilian culture or find suitable work. Thus, many depended on war pensions and other benefits whilst their wives worked.

### *Did They Fight or Didn't They?*

With the advent of new technology, there is an increase in non-combatant and support services in militaries (Connell 1992). Interestingly, most of my informants did not play an active combat role in the war, as the majority were support troops. Support troops are those who are not actively engaged in combat, but who are part of the infrastructure that maintains those soldiers who are.<sup>3</sup> There are a disproportionate number of GWS sufferers who had the role of medical assistants, nurses, theatre technicians and chefs. Their expression of being unmanned may be linked to their lack of warrior role, the absence of a chance to fight and their anomalous role as carer in the military. It is possible that this is related to the contradictory roles in the forces and in the war, whereby they performed a “feminine” task of nurse, carer, cook, provider.

Most join the forces to fight, to be a pilot, to drive a tank (Jones 2004); but the majority of sufferers found themselves in much less masculine and exciting jobs. As mentioned above, the reading of masculinity as warrior involves a clear distinction between the protectors and protected, masculinity and femininity; yet these soldiers had roles which blurred this strict notion of masculinity. GWS may have something to do with this contradiction of soldier role, but carer job. It must also be remembered, in light of the discussions contained in Chapter 3, that support staff such as chefs, medical technicians and nurses are involved in work that transcends body boundaries. They deal with liminal and risky substances.

3. Arms of the military are divided into three main groups: combat or “teeth” arms (infantry, tank crews), combat support arms (engineers, artillery), and combat service support arms (anything else, i.e. medical support, clerks).

As the military is central to the creation of dominant masculinities, the men who join the forces can be seen as striving to achieve an ideal form of masculinity that emphasises strength, mastery, violence, protection and rationality. Many soldiers I spoke to suggested that they were pleased to have been chosen to go to war in that “this is what I was trained for” or “it’s my job”. They had longed for the opportunity and suggested that those who did not get it remained jealous. As Barrett suggested, the US Navy has “an elaborate system of awards and rituals that reinforce the value of demonstrating mastery, especially successful performance under pressure [...] These organizational practices – surveillance, testing, recording, keeping career records – begin to shape and guide the passions of these men. They yearn for the opportunity to demonstrate prowess under pressure” (1996: 136). The question remains: what happens when they simply do not get an opportunity to demonstrate such prowess? As mentioned above, many of the sufferers of GWS were support troops in the war who simply did not get an opportunity to fight or even see the enemy. They had roles of chef, nurse, medical technician and clerk, which meant they were away from the front lines and were, thus, denied the opportunity to fight.

Barrett (1996) found that in the US Navy supply officers (support troops) were considered the lowest status in the Navy. Combat specialists often referred to them as “supply pussies” or “suppo weenies” – the use of the metonymy of small genitalia connoting lack of virility and power in this culture. Unlike aviators and surface warfare officers, “supply officers are not permitted the traditional masculine experiences: the opportunity to take risks, to command and be in charge, and to be autonomous” (Barrett 1996: 139). If GWS can be seen as an expression of unmanning, then the vocation in the military and their role in the actual war must be seen as a contributing factor.

If fighting and going to war are the ultimate expressions of masculinity, what happens to those who are denied it? Most men join the military to fight, to kill, to use a gun. The opportunity to go to war is seen as a positive experience of “proving oneself”. Yet the majority of sufferers did not get such an opportunity. Indeed, 16 per cent of sufferers I interviewed were not deployed to the arena of war. This means that they remained behind, were not sent to the Gulf and did not participate in the war at all. In total, 78 per cent of my GWS sufferer informants were either support troops or non-deployed.<sup>4</sup>

4. In actual fact this number may be higher. Of the 45 sufferers I interviewed 38 told me their role in the military. Thirty-five of these were either non-deployed or support (combat and service support). This means that of those sufferers who gave this information 92 per cent were non-deployed or support. Others may have been support, but it was not clear from their answers.

Even for those in combat roles, there was little opportunity to fight. After months of preparation, the ground war lasted for less than 100 hours. Many felt disappointed and described the war as a letdown. As the British commander, Sir Peter de la Billière wrote, “some soldiers, inevitably, had a feeling of anticlimax. For men who never fired their weapons, or had a real go at the enemy, it all seemed a bit of a waste of time” (1993: 300). Many also suggested that they did not do what they set out to do: a persisting sentiment, particularly in light of the more recent conflict in Iraq, is that “the job was not done”.

My very first meeting with a Gulf veteran was dominated by his discussion of the experience of coming back from war and subsequently leaving the forces. He focused on the problems veterans have: from discovering that they cannot get a job to their wives’ difficulty in running a household in the absence of the social support found on a military base. He said,

You get these problems all the time after the wars. Readjustment, getting life back to state where thinking for yourself, but I still feel that things are very different on the Gulf side. Maybe because there was no end. Started, but no end. Just told to stop firing now. Firing and then told not to and still being fired at. Seems like it was a game.

It has been suggested that killing is a pleasurable part of war for soldiers: killing “was intrinsically glamorous.”<sup>5</sup> Bourke describes the pleasure of war as experienced by Vietnam veterans: it was like ‘getting screwed the first time’ and gave men ‘an ache as profound as the ache of orgasm’<sup>6</sup>. In the words of a black Muslim Marine, ‘I enjoyed the shooting and the killing. I was literally turned on when I saw a gook get shot’<sup>7</sup> (Bourke 1999: 32). It has been suggested that Marine Corps training for Vietnam produced a degraded masculinity (Eisenhart 1975) and the soldiers were whipped up into a state of quasi-sexual excitement. The war experience did not provide them with sufficient outlet, though, and the “ordinary Marine, whipped up to a pitch of sexual frenzy, never ‘got his gun off’” (Shephard 2000: 356) – the result of which was suffering Vietnam vets who were seen as dysfunctional supermen. Evident in the above historical descriptions of killing and war is the sexual nature of it. War is highly sexualised, as is the language of war (Littlewood 1997).

5. Michael Herr, *Dispatches* (London 1979) p.199

6. Philip Caputo, *A rumor of war* (London, 1977), p.268; and James Jones, *The Thin Red Line* (New York, 1962), p. 197.

7. Mark Baker, *Nam: The Vietnam War in the words of the men and women who fought there* (London, 1982), p. 51.

The inference is that killing is essential in the experience of war and those who are unable or did not get the opportunity were at risk. Bourke found that in the First World War men “unable to cope with killing were an aberrant group. Frighteningly, psychiatrists recognised that more men broke down in war because they were *not* allowed to kill than under the strain of killing ... The absence of any outlet for aggressive tendencies put soldiers at risk of psychological disorders, argued numerous psychiatrists in later conflicts” (1999: 248–49). Again, it should be remembered that the ground war was very short and likely added to the general feelings of dissatisfaction and discontent, predominant in discussions of GWS.<sup>8</sup>

As mentioned previously (Chapter 5), wives, mothers and partners play a major role in labelling illness as GWS. On many occasions veterans explained that their wives spoke about their partners to other wives and this is how they came to suspect GWS. I would suggest that the dominant role of women in identifying illness in their partner and pushing for a GWS diagnosis may be caused by an underlying dissatisfaction with their husband’s behaviour and performance. Many women I spoke to said that their husbands were irritable, distant and emotional and said that this is when they first began suspecting something was wrong. When the men returned, they seemed like strange creatures. In the media report of the recent conflict in Iraq, it was said that women were often apprehensive about the men’s return because they were used to being on their own and were worried about having to start the relationship again (Kennedy 2003). Thus, GWS must be seen in the context of men returning home from war and in so doing altering the way of life women had experienced. Men returned home and seemed different from the way they had been before. In addition, in most cases, men returned home full time as most left the forces soon after the war as a result of “Options for Change”. Women may be eager to maintain their partner’s identity as a soldier, through

8. Frustrations about the Gulf War and lack of combat experience was depicted in the 2005 film *Jarhead* which showed US Marines in the Gulf War battling months of boredom and a sense of isolation rather than enemy combatants. Once the Marines eventually advance through the desert they face no enemies on the ground and the real threat seems to be from accidental fire from their own side. Finally given a combat mission, Swofford, a sniper, and Troy, his spotter, are ordered to shoot two Iraqi officers, but moments after they pinpoint one of the officers in his sights, another team of Marines appears and calls in an air strike. Desperate to make a kill they plead to let them take the shot. When his pleas are denied, Troy breaks down in a fit of despair and weeps. Moments later the airport is bombed by U.S. warplanes and the two return to base to discover the war is over. They bemoan the fact that they never fired their rifles.

GWS and veterans' associations, in order to preserve or re-establish status. Furthermore, employing GWS may be an acceptable way to explain the failures and inadequacies they observe in their husbands. Their men may not have lived up to the masculine ideal and, thus, the women in their lives may have sought an explanation on their behalf.

## Gender Anxiety

GWS narratives invariably point to anxieties about gender identity and masculinity. The veterans I spoke to often discussed a lack of libido and impotence. This theme is further developed in narratives of GWS, which focus on the notion that veterans suffer from "old people's diseases", "women's diseases", "old women's diseases". It would seem that veterans, through their bodies, are expressing their sense of being unmanned. Their experiences made them feel as though their masculinity was under scrutiny and came up lacking.

Women are "othered" in a particularly intense way within military culture. Discipline, "obedience, compliance, and exacting detail, ideals that are depicted as 'tough' and masculine, depend upon contrasting images of the feminized 'other' – being undisciplined, scattered, emotional, unreliable ... One way to emphasize discipline, endurance, and rationality as masculine traits is to depict lack of discipline, unreliability, and emotion as feminine" (Barrett 1996: 139). What GWS may be expressing, in part, is a contradiction within these men, who perceive themselves as containing what they were taught were negative, feminine qualities. They were trained by the military to detest and avoid such feminine qualities (fatigue, failure, emotion) yet they find themselves embodying them.

One commentator spoke about the more recent war with Iraq in terms of a response to twenty-first century white male malaise and emasculation. Norman Mailer (2003) suggests that the real reason the US went to war with Iraq was to boost the white male ego; the ongoing malaise of the white American male needed a remedy. Their dominance in sport was eroded, with "black genius" prevailing. The women's movement had taken hold and "the old, easy white male ego had withered in the glare". This key group for President Bush's political footing was floundering. "As a matter of collective ego, the good white American male had had very little to nourish his morale since the job market had gone bad, unless he happened to be in the Armed Forces. There, it was certainly different. The Armed Forces had become the paradigmatic equal of a great young athlete looking to test his true size" (Mailer 2003). White men still dominate the armed forces and,



importantly, they dominate the highest ranks and most highly regarded trades. If we cannot find our machismo anywhere else, says Mailer, we can certainly settle in on the interface between combat and technology. This passage reveals the way in which war and fighting are intimately linked not only with individual masculinity, but the collective masculinity of a culture.

The problem of linking masculine gender with bodily changes has been a matter of anthropological concern. In his monograph on his struggle with a spinal chord tumour, Murphy exposes the contradictions that emerge as “weakening and atrophy of the body threaten all the cultural values of masculinity” (1987: 94). A study of elderly US veterans’ ideas about masculinity sheds light on Gulf veterans’ difficulty in coming to terms with aging and illness and their need to reformulate gender identity. In this study ideas about gender have been investigated in veterans suffering from prostate cancer (Stansbury et al. 2003). With prostate cancer and treatment, difficulties associated with chronic illness are “multiplied as sufferers come to terms with assaults on embodied bases for gender identity, most directly in the forms of urinary incontinence and impotence” (Stansbury et al. 2003: 177). The authors conclude that coming to terms with disease, chronic illness and aging may be challenging for men who adhere to an inflexible gender schema. They found that prostate cancer patients reaffirm a strongly moral normalising discourse about “being a man” yet tend to separate roles and values from male physical and sexual attributes (Stansbury et al. 2003).

Research also suggests that men with a fixed view of masculinity may have worse health outcomes (Stansbury et al. 2003). Health psychologists have cast the relationship between masculinity and coping in a problematic light. Eisler and Blalock (1991) suggest that a “male behaviour template” underlies aggression, combativeness and other aspects of some male coping styles; it can lead individuals with rigid ideas about masculinity to suffer greater stresses with illness than are suffered by those who do not hold such views. Inhibited emotions, over-reliance on aggressive behaviour, a need for control and an obsession with competitiveness are noted as basic dispositions that can account for problems. Eisler and Blalock see a “strong commitment to masculine gender role cognitive schemata” (1991: 49–50) at the heart of the problem. It has been suggested that men

[W]ho most strongly retain an image of male physicality against the realities of aging and diseased bodies are most at risk for stress, depression, and difficulties with personal support networks. Successfully coping [...] involves redefining the self, at least in part through very partial transformations of the normalizing ideology of masculinity. This is not an act

of resistance: it is a gentle, if certain, rounding of cultural edges. (Stansbury et al. 2003: 196)

The patterns the authors saw may well reflect a masculine image that emerges from the military's role as a socialising force for men, even as the monolithic nature of masculine constructions in the military may be overstated (Barrett 1996; Agostino 1998; Connell 2000: 215).

## **Leaving the Military**

GWS sufferers endure gender anxiety where they have moved from an extremely ritualised and structured masculine world into a much more chaotic life. They express this existential crisis by way of their bodies and the symptoms they suffer. Veterans experience a crisis of personhood, identity and masculinity in a post-combat, post-forces context. Gulf veterans' reported health problems are worse the lower their rank is, and after they have left the forces (MRC 2003). As mentioned previously, most of the veterans I spoke to left the military during the period of "Options for Change". What this meant was that almost immediately after the dramatic experience of war they found themselves in civilian life. Whilst they were in the forces they had a structured identity – that of a masculine soldier, warrior, employed man, hero. They then found themselves in an entirely new world where they had to fend for themselves: pay bills, find a job and struggle with the lack of established identity.

It could be suggested that ascribing to a GWS narrative enables a floundering veteran to anchor himself to a complete and fully-formed identity. Beck and Giddens have both suggested that living in contemporary society requires a reflexive "Do it yourself" approach to one's biography (Beck 1992: 135). The GWS movement provided an attractive template to reconfigure veterans' identity. This identity is one of fractured hero, created out of illness and of being wronged. GWS sufferers often redefine their identity along the lines of illness and the community of sufferers they inhabit, yet their identity as GWS sufferers acts as a constant reminder of their status as veteran, soldier, warrior in the Gulf War. Their new identity, therefore, continues their association with the Forces.

Many veterans explain that they found it difficult to move from military life to civilian life. My first meeting with a veteran, mentioned above, surprised me in that instead of focusing on the illness itself, he emphasised other social and economic factors. This veteran, one of the leaders of the GWS movement, spoke mainly about veterans'

experiences of returning home, of leaving the military, and of unemployment and pension problems. He suggested that the military sets men up to be dependent; they are taught not to think for themselves, but this causes problems when they leave the forces. Soldiers and ex-soldiers can identify each other from a mile away,<sup>9</sup> as though their bodies will always be military. Although other veterans seemed to focus more on symptoms and the illness itself, I found that my conclusions were to come full circle, back to this first meeting with the veteran mentioned above.

Veterans explain that it was difficult to adjust to a life where one had to fend for oneself. In the military, they explain, they were told when to eat and meals were provided for them. Their bills were paid, accommodation was arranged: their life was entirely routine and organised. Not so in civilian life – and many suggested that this was a difficult reality with which to come to terms. Employment was also not as straightforward as they presumed. Finding that their identity as a soldier and war veteran was not as valuable as they had expected was an unsettling realisation for some. Many veterans say they found it difficult to find a job and for the ones who did it was often difficult to work with civilians. Civilians and military people were different animals, I was told on numerous occasions.

A major aspect of military identity is its perceived dominance over civilians. Military careers are positioned as demanding more from the average person than civilian careers (Agostino 1998). There is an “us and them” mentality; civilians are associated with the protected and the feminine. These boundaries are blurred when the veteran leaves the forces: he is neither civilian nor soldier. Although the majority of sufferers I interviewed were ex-military and, technically, civilian, they maintained a fierce distinction between themselves and the rest of civilian society. When speaking about the centrality of the distinction between civilian and soldier for the warrior masculine ideal, it is important to remember that there are a high proportion of sufferers who were in the TA and reserves. They, too, blur these boundaries from the very outset. They are neither civilian nor military. They are seen as not fully military by regular soldiers, yet seen as military by civilians. It would seem, therefore, that there is a tension between the veteran’s life within civilian society and their previous identity as a soldier. In the military their identity was anchored in being better than and different from civilians, yet they now find themselves as part of this denigrated culture.

9. I was often told that this was due to the way they dressed, but also the way they moved and always looked cautious and watchful.

Leaving the military behind also meant losing an identity and comrades. Much of military life is based upon close relationships and the community of soldiers. Most of my informants fondly recall the close friendships they had and missed the camaraderie of military life. The veterans' association fills that absence to some degree, creating a community of ex-soldiers along the lines of the military environment. It surprised me that although it was the military that they held responsible for making them ill, the veterans I spoke to remained fiercely loyal to the forces. Many told me that their years in the forces were the best in their lives and many regret leaving. Veterans often told me that they would go back to serve if they could. During interviews in their homes I would see pictures and souvenirs from the war displayed in prominent positions. For example, one soldier had a huge wedding picture above his mantelpiece in which he was dressed in full uniform. I was surprised by this as the veteran had been a TA soldier. Instead of a military uniform they wear their veterans' association uniform with their regimental tie. It was clear that veterans highly valued their military identity and tried to retain it. The identity they re-created in the form of GWS sufferer places their military past at the forefront.

Such ongoing loyalty to the forces has been seen in the US as one major constraint for veterans in thinking of their illness as GWS (Shriver et al. 2002a). The veterans interviewed by these authors remained very patriotic, which "often led to difficulty connecting their sickness to their wartime experience as they had to reconcile their patriotism with their belief that the government is not acting appropriately" (ibid.: 131). By participating in military culture, individuals learn to value group cohesiveness highly and to avoid any activities that counter unity and camaraderie. There were ways, however, to overcome such constraints. Many veterans "replaced their original sense of solidarity with all soldiers with a sense of connection to other veterans with similar understandings of Gulf War illness" (ibid.: 132). Far from constraining the GWS movement, I would suggest that an ongoing focus on the military as the epitome of patriotism and heroics reinforces labelling illness as GWS. GWS means that the sufferer is always linked with their heroic past and their military identity.

A view of gender identity as contingent, negotiable and fluid has become important in both medical anthropology and in anthropology in general. Writing about gendered outcomes in cancer, for example, Manderson (1999) examines patient narratives, raising the issue of renegotiating gender and sexuality. She noted that men seek to "remain masculine" when faced with the iatrogenic collateral damages implied by prostate cancer treatment. This contrasts markedly with

women's struggles to "recover femininity" after surgery. Stansbury et al. note that the "negotiation of chronic illness can imply fundamental redefinitions of self and identity, and that these reformulations may be quite different from a reassertion of normalcy. In some illnesses, transformation involves the blending of identity and disease diagnosis" (2003: 182). The authors point out that Estroff, (1993) showed how patients diagnosed with schizophrenia become the illness as they redefine their identities according to the schizophrenic label. Similarly, GWS sufferers become their illness and the illness itself becomes an organising feature in their life: a lifestyle. Unemployed and unable to work, many of these men organise their time around the illness: internet searches; doctors' appointments; and writing letters to and contacting lawyers, doctors, the government; and contact with other sufferers. The illness and its accompanying battle for recognition becomes the central focus in their lives. More recently, authors have begun to analyse these profound identity transformations as a reaction to social processes and contexts (van Dongen 2001; van Dogen and Reis 2001).

## **The Military Context**

The above discussion focuses on the way in which veterans from the Gulf War experienced a crisis of identity as they moved from military to civilian life. This crisis is not unique to the Gulf case; similar difficulties have been reported in other military groups. We have also seen that Gulf veterans faced particular difficulties in addition to the hurdles arising out of a change in status as a soldier, but problems are not isolated to those moving away from military culture in that soldiers are seen as representing a particular group with unique troubles. Social and psychological problems have long been associated with military men and women. The military context and its unique difficulties is of paramount importance to GWS sufferers and is worthy of investigation to help us better understand all aspect of their particular mileu.

Among evidence of special difficulties is the fact that a disproportionate number of the single homeless population have a background in the armed forces (Anderson et al. 1993; Randall and Brown 1994; Gunner and Knott 1997). Domestic and other forms of violence have also been seen as a military problem. After the recent conflict in Afghanistan the media reported domestic murders committed by returning troops. Timothy McVeigh, the man responsible for the Oklahoma bombing, and John Allen Muhammad, the Washington

sniper,<sup>10</sup> were both Gulf veterans. GWS was briefly implicated in both of their crimes. Some advocates, such as Haley, continue to link such behaviour to brain abnormalities caused by GWS (Serrano 2003). There have also been cases in the UK of Gulf veterans killing; GWS has been at times named as a factor. Although there have been a small number of cases in addition to these, which have reported the uncontrollable, violent nature of the returning Gulf veteran, the general representation is of an enfeebled man made sick by his government.

It has been suggested that war and returning from war result in impotence and emasculation. Shephard (2000) has noted that women reacted to the First World War with a powerful increase of libido, whereas impotence was one of the principal side-effects of shell shock.<sup>11</sup> A great deal of attention has been paid to the way in which demobilisation of a country's fighting force may threaten to "feminize the male population" (Randolph Higonnet et al. 1987: 38). Showalter and others have reported the literal and symbolic impotence from which First World War veterans suffered. For returning First World War veterans, being in the company of women was "strange"; women's pity as well as their new power was a source of anger. Furthermore, the war had "desexed" them and rendered them impotent (Bourke 1996: 166). Theweliet (1989) writes about the constant danger of dissolution which threatened the Freicorps soldier, a danger which was more internal than external. Recent representations of the Vietnam War have been depicted as an attempt to shift the male lack<sup>12</sup> which attached itself insistently to the returning veteran (Jeffords 1994). Silverman (1992) suggests that the male subject is brought into a traumatic encounter with his lack in the situation of war.

In her work Silverman (1992) traces the consequences for masculinity of a particular historical upheaval: that of the First World War and the recovery period. In her psychoanalytic analysis, Silverman isolates the "equation of penis and phallus as a privileged site for the investment of collective belief, and it will emphasise the degree to which our society's entire 'reality' depends upon the maintenance of that

10. Muhammad, with his young conspirator, was responsible for a three-week campaign of terror that left 10 people dead in and around the US capital in October 2002.
11. Shephard (2000) argues against the historical cliché that a collective impotence descended on the Western male: the real point about shell shock, he writes, is that it undermined men's authority.
12. This is a difficult term, but in absence of an alternative it will, hopefully, suffice. By "male lack" or, simply, "lack" I mean to suggest the absence of desired qualities: inadequacy, lack of potency and dominance. It relates to the Freudian idea of "castration" from which all males are said to suffer. It can be seen in symbolic terms to suggest a loss of potency, power and authority.

equation" (1992: 8). She explores Hollywood movies produced soon after the war, with their pre-occupation with male lack and gender role ambiguity. Silverman argues that these movies attest to a massive loss of faith in traditional masculinity. They dramatise the implications of this dissolution not only for gender and the family, but for the larger society. The focus is on the veteran returning home and not adapting well to the new situation. Sometimes "the veteran also finds himself strangely superfluous to the society he ostensibly protected during the war; his functions have been assumed by other men, or – much more disturbingly – by women. These texts thus dramatise the vulnerability of conventional masculinity and the larger dominant fiction to what I will call 'historical trauma'" (Silverman 1992: 53). There is the sense that the veteran is so scarred by the experience of a loss of potency and power that he finds it impossible to re-enter society.

The movies are structured around the castrated male: the penis-phallus equation has been disrupted.

[Even] under the most auspicious circumstances, moreover, the fiction of a phallic masculinity generally remains intact only for the duration of the war [...] For the society to which he returns, moreover, he represents a sorry travesty of "our fighting men and boys," a living proof of the incommensurability of penis and phallus. Because of the resulting crisis of faith, "reality" itself is at least temporarily jeopardized. (Silverman 1992: 63)

These movies focus on the re-alignment and restoration of the dominant fiction. Post-war periods are characterised by an attempt to re-configure masculinity. The wars mentioned above involved long, drawn-out hostilities that affected societies greatly. In comparison, the Gulf War was short and did not affect the home society from which soldiers came: it remained localised. Instead of all of society re-figuring male authority, it would seem that this is occurring amongst the culture of sufferers and in the bodies of men.

### *Post-combat Syndromes*

Unwin et al. (1999) suggest that the discovery that active military service leads to long-term adverse health effects is not new. Each modern war has produced its own post-combat syndrome. Although they are represented by similar clusters of symptoms, individual wars generate their own physical focus, diagnostic terms and explanations. Such a reading of post-combat syndromes corresponds with the interpretation of illness as metaphor (see Introduction). Gulf veterans respond negatively to this line of inquiry as it undermines the status of GWS as a new, unique and

physical illness. Seen as characterised by unexplained medical symptoms, the current thinking about post-combat syndromes can be seen as allied with theories of somatisation arising from psychological distress.

War syndromes “present as clusters of unexplained symptoms for which no demonstrable organic cause can be found. They reflect the health concerns of their time, and their focus alters as society’s fears change as a result of developments in medical science” (Jones 1999a: 4). Late nineteenth-century wars, for example, produced combat syndromes characterised by illnesses involving the heart. This was a reflection of the medical focus on the heart during this period, mainly because of new medical findings. Health issues were a major source of concern for veterans and led to the formation of pressure groups campaigning for improved benefits and treatment (Jones 1999a). The 1960s, however, “witnessed a cultural change as the rights of the individual were promoted in favour of the duties of the citizen to the state” (Jones 1999a: 4). As Jones suggests, the increasing litigious nature of Western society as well as the increasing role of the media’s sympathy to ex-servicemen’s issues mean that veterans’ groups are more likely to campaign for health issues.

**Table 1:** War Syndromes

War Syndromes characterised by unexplained medical symptoms

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**Pre-1914**

Soldier’s heart, irritable heart, palpitation, Da Costa’s syndrome, disordered action of the heart, nostalgia, wind contusion

**First World War (1914–1918)**

Shell shock, effort syndrome, neurocirculatory asthenia, war neurosis, gas hysteria

**Second World War (1939–1945)**

Non-ulcer dyspepsia, psychoneurosis, battle exhaustion

**Vietnam War (1965–1974)**

Effects of Agent Orange; post-traumatic stress disorder (PTSD)

**Gulf War (1991)**

Desert Storm Syndrome, Gulf War Syndrome, Gulf-related illness

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Source: Jones and Wessely (2003a: 2)



Although challenges to the US and UK military are rare, GWS is not the first time veterans have confronted the government over environmental exposures and related illness claims. Scott (1992, 1993) has documented Vietnam veterans' challenges to the US government over exposures to Agent Orange. Less publicised claims have also come from Atomic veterans: those members of the US armed forces who were exposed to ionising radiation from atomic and nuclear weapons tests between 1945 and 1963 (Shriver 2001).

The Vietnam War produced two divergent syndromes: one that was linked to Agent Orange and one which focused on psychological effects of traumatic memories – PTSD. The former can be seen as similar, in part, to GWS in that it focused on war-time exposure to toxins, producing a wide range of medical complaints including birth defects. Similar to GWS as well, the link has not yet been proven. Young's (1995) work on PTSD looks at the social and cultural milieu of the creation of a new illness category. Developed in American military hospitals, PTSD provided an avenue through which Vietnam veterans could assuage the guilt they felt over the war. Young suggests that the category transformed the veteran from the aggressor into the victim. The diagnosis has now become available for taking on other troublesome questions regarding the attribution of personal or official responsibility in a contractual society. One of the reasons I became interested in GWS was the fact that regardless of the acceptance of PTSD as a defined and war-related category, Gulf veterans dispute a link between their illness and PTSD (Chapter 5; see also Kilshaw 2008).

Post-combat syndromes are in the domain of psychiatry and have been constructed by the historical relationship between psychiatry and the military. Although previously thought to be physical in nature, such syndromes were transformed into the realm of psychiatry and seen as conversion or hysterical disorders. Again, boundaries are blurred as that which was thought to be the realm of women – hysteria – was converted into an illness from which men could suffer. War provokes the re-interpretation of such issues and the blurring of boundaries. The emphasis veterans and their advocates place on the physical nature of their illness is linked to the fact that PTSD and other psychiatric/psychological problems contradict entirely the idea of masculinity which embodies strength and rationality under pressure. The true soldier is prepared and does not crack under stress. Furthermore, in the military, saying one may be having psychological difficulties is likely to prevent one from being allowed to do one's job (for example, one's gun will be removed). This adamant denial of psychological factors of the illness, though, is also rooted within a deeper cultural stance, which deems psychiatric and psychological problems less worthy of attention.

## Conclusions: Embodying Male Lack

As mentioned in the Introduction, anthropologists have argued that physical bodies are shaped by culture, by means of widely held models, images and metaphors. Metaphor becomes embodied (Kirmayer 1992), whilst the body is a rich metaphor for society (Scheper-Hughes and Lock 1987). As we have seen above, the link between the individual soldier, his body, his masculinity and the nature of the surrounding culture is direct. It is not surprising, then, that bodies of veterans embody their experiences and post-combat milieu. Following these arguments, GWS can be interpreted as the embodiment of a failure to reach the masculine ideals espoused in the military and in the wider society. Just as their pre-war bodies were shaped by culture, particularly military culture, so too are their post-war bodies. The metaphor of impotency, unmanliness, fatigue and weakness has been embodied.

The military is a gendered and gendering institution and, thus, it is not surprising that narratives of GWS concern themselves with issues of gender and masculinity. The way in which there is a precedent of difficulties amongst military personnel has been discussed in order to understand the context of the illness better. One of the contradictions inherent in the masculine culture of the military is that, while the organisation creates experiences of inevitable failure, there is no legitimate way for members to justify failure (Barrett 1996). GWS provided an explanatory system to explain each person's and the collective group's experiences. The majority of veterans I interviewed had a number of threats to their masculinity: (1) not fighting, the lack of the warrior role, (2) their role as support troops within the war and the military, (3) Options for Change, with its resulting redundancies, (4) women and civilians entering the military, (5) the changing face of the military, and (6) the dominance of and dependence on technology.

This chapter has outlined the way in which the military establishes strong boundaries which define and embody an idealised masculinity. I have revealed the way in which these boundaries have been blurred in general, but in the lives of GWS sufferers specifically. As discussed in Part II, veterans see their bodies as vulnerable, porous and "leaky". This can be seen as a reflection of wider boundaries which they see as no longer secure. The military itself is a boundary breaker: it attacks and owns the body. Historically, war blurs boundaries. The absence of women in First World War combat, for example, "had an additional component: gender roles were rendered more fluid in wartime as men were required to carry out many tasks that had formerly been the preserve of the opposite sex" (Bourke 1996: 133). For Gulf veterans

external boundaries were compromised: women and civilians entered the military, veterans left the confines of the military and entered civilian life. A world full of structure and rules was suddenly replaced by one of chaos. The human rights laws, entrance of women and civilians into the forces, the new emphasis on peacekeeping as opposed to fighting could all be seen as weakening the military and making it vulnerable to outside, undesirable forces. Boundaries and borders which used to be structured were now penetrable and indistinct. Similarly, boundaries between enemies and friends were hazy, as can be seen in GWS theories of causation and stories of friendly fire. Veterans' discussions of their illness reflect these blurred boundaries, as in discussions of auto-immune diseases and leaky bodies.

However unique, GWS must also be seen against its more general cultural backdrop. This illness could only arise as it did out of a specific cultural milieu. This environment gave rise to but also shaped the illness. An illness can be seen as a conduit for the expression of social ills and social concerns; it may demonstrate shared sentiments, common fears or tensions between particular groups. GWS can be seen as part of a group of new illness movements such as CFS, MCS and FM, which are shaped by common cultural themes; it is to this that I will turn in the next chapter.

## Conclusion

# **GWS AND WORLD TRADE CENTRE SYNDROME**

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One day in 2003, having completed my fieldwork, I was looking at various GWS websites. A woman had posted a message saying that she believed herself to be ill with GWS as her symptoms were the same as those she had seen described on the message board. She had not been in the Gulf War. In fact, she was not a soldier. Living in New York in 2001 at the time of the World Trade Centre terrorist attacks, she believed that the terrorists, from the Middle East, no less, had been carrying viruses or toxins on the planes with them. This scenario illustrates the way that themes contained in GWS resonate with other illness narratives, health beliefs and wider cultural issues and anxieties – in particular, the focus on vulnerability, notions of risk and the increasing focus on health and belief in its elusiveness.

### **GWS: An Illness of Our Time?**

I became interested in GWS because many of the themes in modern life seemed to converge in this illness. It is a new illness which highlights many of the anxieties and concerns of twentieth- and twenty-first-century life in the UK (US and Canada). As I studied this intriguing condition I became more aware of just how true this was. It seemed that every new health scare reflected some aspect of GWS and the concerns of its sufferers. The phenomena of MMR, allergies, concerns about mobile phones, food sensitivity, amongst others, share common patterns with GWS: themes of toxicity and contagion; feelings of body

vulnerability; a focus on the immune system; the link between the body, health and identity; as well as the belief in ever-present risks and dangers. Beyond simply embodying our beliefs about health and illness, I came to realise that GWS also expressed wider societal concerns as well as contradictions very specific to the men and women whose lives I studied.

The previous three chapters focused on the unique aspects of GWS and how the illness can be seen as a specific entity that arose out of veterans' attempts to make sense of their experiences: of their time in the military, the Gulf War, "Options for Change", and leaving the military, amongst others. This chapter widens out the discussion of GWS to reveal the way in which GWS can also be seen as characteristic of the wider society in which it is found. In order to understand GWS, the issues which helped to shape it, as well as the cultural beliefs which enabled it to emerge and gain such a foothold, we must see it in its wider context. An illness will only be accepted and gain a position as an authentic condition if it resonates with a larger cultural framework which makes it intelligible. As Kirmayer suggests, whether an illness representation gets taken up by many people depends on a number of social factors, including, the "aptness of representations in terms of coexisting cultural representation and practices" (1999: 279). Every culture has its fears, which can help to frame and to construct social facts such as illness.

In context, people's words and actions makes sense. As anthropologists, we are always widening the context to make people's actions intelligible. To do so in the GWS case, it is necessary not only to make sense of the illness by looking at military life, but also to see how this illness arose as part of a wider set of circumstances. In doing so, we see that GWS shares a great deal of features with other Euro-American emergent and contested illnesses. This concluding chapter looks at this wider context and, thus, relates to the first chapters of the book, with their discussions of issues of risk, bodily vulnerability, the immune system and shifting boundaries. Whilst necessary to place GWS in its wider context, it is important that the specific is never overlooked. This concluding chapter reveals the delicate balance that must be met to understand this illness: the need to see GWS as part of larger phenomenon is tempered with an understanding of it as a unique illness expression.

*Health Scares: From MMR to World Trade Centre Syndrome*

An important way of disseminating health information and expressing anxieties about health is in the form of rumours and gossip, often connected to media reporting. The media picks up such stories and circulates them, both reflecting cultural anxieties and intensifying them. GWS remains a focus of media attention and stories continue to circulate about this illness. White (2000) investigated rumours in postcolonial Africa to uncover the world of rumours and gossip. She found that vampires provided a powerful way for Africans to talk about ideas and relationships that begged description. The premise in White's work is that:

[P]eople do not speak with the truth, with a concept of the accurate description of what they saw, to say what they mean, but they construct and repeat stories that carry the values and meanings that most forcibly get their points across. People do not always speak from experience – even when that is considered the most accurate kind of information, but speak with stories that circulate to explain what happened. (2000: 30)

The circulating stories aid people to understand what was previously incomprehensible. People fit their experience into these stories; rumours and stories help them to make sense of their experience. White has made a similar case for North American UFO abduction narratives which, she argues, debate race, reproduction, the role of women in childcare and abortion. She suggests that it "is not that there are no other places where these issues can be talked about in contemporary American society, but that they are considered so important that they are spoken of at many sites" (2000: 29). I think such a reading can aid us in looking at GWS and health scares, and the repetitive themes we see in them.

It would seem that every day there are media stories about the latest health scare. More and more media reports suggest that you may be suffering from a range of conditions. Worryingly, many suggest that you may be suffering from sinister conditions, yet remain oblivious and symptom free: "Illnesses you didn't know you have", as one recent headline implied. It would seem that everyone is ill, and these stories suggest you need a series of tests to uncover these unknown conditions. Media reports increasingly focus on the idea that you can be ill and not know it. Even the absence of discernible symptoms does not necessarily point to well-being. Such stories focus on the need to uncover dormant illness, reflecting the veterans' assertion that each individual has unique, dormant and opportunistic risks which lie in

wait. Health scares tend to gain hold because they hit on present fears. The ongoing panic created by the MMR vaccine took hold, in part, because it touched on an already increasing anxiety about vaccinations present in the UK.

The way in which GWS is talked about and portrayed is similar to the alarmist health stories one so often sees. Following White, I would suggest that the issues contained in GWS are so important that they are spoken about in a variety of ways across a variety of sites. GWS is about much more than itself: people talk about it and are concerned with it. The stories about GWS continue to circulate: it is a potent package that allows people to talk about the matters that are important to them and helps them to make sense of their experience.

## **Risk and Vulnerability**

As discussed in previous chapters, veterans see the world as full of risk. Acting in accordance with the Euro-American worldview, they are likely to view symptoms as pathological and interpret them medically. The popular belief is that the physical world is a potentially hostile and toxic place that erodes health and wellbeing. Linked to this health anxiety are a general sense of uncertainty and a mistrust of science and scientists. GWS should be seen against the backdrop of increasing anxiety about health and a heightened link between identity and the body, which we find in the present cultural milieu.

The “‘objects’ of scientization also become the subjects of it, in the sense that they can and must actively manipulate the heterogeneous supply of scientific interpretations” (Beck 1991: 157). This questioning of science and the accompanying process of picking and choosing from available scientific information has been shown to characterise GWS. Yet this process can be seen as characteristic of the larger society in which GWS emerged. There is no scientific monopoly on discussions of risk as there is rarely expert agreement on what constitutes a risk, and how it might be managed. As a result, public uncertainty increases as does criticism. Think of the MMR debate which emerged due, in part, to conflicting notions of risk within the scientific community and an accompanying mistrust of doctors, scientists and the government. Knowledge is contested between lay people and scientists, but also among scientists themselves. People are increasingly sceptical of what scientists have to say, and use their own experiences or those around them to fill in the gaps. In new illness movements the sufferers themselves are seen as the experts. They are experts by virtue of their experience. As Shorter notes, the theme of medical incompetence and

indifference runs through the CFS movement “which elevates the patients’ subjective knowledge of their bodies to the same status as the doctors’ objective knowledge. This presumption of privileged self-knowledge of one’s body dovetails perfectly with media marketing strategies” (1992: 317).

New illness movements such as CFS and GWS offer a set of systemic critiques, or critiques of the biomedical system, so that sufferers can make sense of their personal histories of seemingly haphazard troubles (Dumit 2005). The networks also “continually *experiment* with and offer new forms of social relationships for sufferers and the public at large to inhabit: these include the idea of illness as a lifestyle [...] which requires cultural respect for differences caused by otherwise invisible illnesses. Other relationships include the notion of the patient as an expert, as a survivor, and as a communicator” (Dumit 2006: 587; emphasis in original).

### *Health and Risk*

What are Americans afraid of? Nothing much except the food they eat, the water they drink, the air they breathe, the land they live on, and the energy they use. In the amazingly short space of fifteen to twenty years, confidence about the physical world has turned to doubt, once the source of safety, science and technology has become the source of risk. (Douglas and Wildavsky 1982: 10)

Douglas and Wildavsky ask why is it that when life is safer and life expectancy has increased people are more focused on risk? The centrality of issues of risk and who is responsible for them is an important factor in understanding the wider culture which gave rise to GWS. Related to this is the paradox of health: although people are healthier than they have ever been, with fewer risks to their health, they are more likely to feel ill and anxious about their well-being. In the Euro-American context, we are more likely than ever before to pay attention to benign symptoms and see them as arising from occult causes. We therefore actively seek explanations for them.

The explanations generally advanced are located in the environment in the form of toxins, viruses and chemicals. Doctors are commonly visited by patients with symptoms and conditions that are attributed by the sufferer to deficiencies in their immune system. Associated with this focus on health is the ever-more intimate connection between health, identity and the self. We see the body as the locus of the self and treat it accordingly. Illnesses and the movements that appear around



them are intertwined with identity. GWS has become a lifestyle for many of its sufferers, defining who they are and how they live their lives. Illness provides a way to make sense of life events and allows one to develop an effective and robust identity. It contributes a kind of biographical kit to interpret past, present and future events. Illness movements provide templates for meta-narratives which enable sufferers to link apparently disparate experiences together into one, sweeping explanation. They give us the sense that everything is connected and explainable and that someone else is to blame – which resonates with Azande witchcraft beliefs outlined earlier. GWS and its movement create a sense of order out of an experience of chaos and post-war/post forces life unravelling. It makes the incoherent coherent.

People are increasingly bothered by, aware of and disabled by distress and discomforts that in the past were deemed less important and less worthy of medical attention. There appears to be a progressive decline in our threshold and tolerance for mild and self-limited ailments. Society's "heightened consciousness of health has led to greater self-scrutiny and an amplified awareness of bodily symptoms and feelings of illness" whilst the widespread "commercialization of health and the increasing focus on health issues in the media have created a climate of apprehension, insecurity, and alarm about disease" (Barsky 1988: 414). GWS and other new illnesses "often assume prominence in the mass communications media and public consciousness before their scientific dimensions have been established" (Barsky and Borus 1995: 1932). It would seem that everyday life is saturated with anxiety about the world around us. Each day there is another health scare about which to worry.

### *GWS and Functional Somatic Syndromes*

We have seen an increasing emphasis on "health", thereby amplifying the public's sense of somatic vulnerability and apprehension of illness (Barsky 1988), which has resulted in the emergence of new illnesses. In the past decade we have seen this trend increase at an alarming rate. We presently find ourselves in a cultural climate of alarm about health, which itself undermines feelings of well-being. This cultural trend of an increased sensitivity to bodily signals has resulted in the construction of new illnesses, labelled "medically unexplained" or "functional somatic syndromes" (Shorter 1992; Wessely et al. 1999a), whose scientific status and medical basis remain unclear. This group of new and contested illnesses include: ME/CFS, total allergy syndrome, MCS, IBS, fibromyalgia and sick building syndrome. GWS has been

squarely situated amongst other “functional somatic syndromes” (Barsky and Borus 1995; Showalter 1997b; Wessely et al. 1999a; Wheelwright 2001; Ismail and Lewis 2006). There is considerable overlap in the narratives and the symptoms of these various disorders (Wessely et al. 1999a). This commonality points to the possibility that the existence of each disorder is itself illustrative of a particular cultural movement.

GWS shares with other new illness movements relevant characteristics which reflect cultural themes and anxieties. Nettleton suggests “the relatively marginalised and neglected set of people who live with MUS [medically unexplained syndromes] comprise an extreme example of the lives of the majority of people in ‘risk society’” (2006: 5). Although at the margins, she argues, they are emblematic of the mainstream. As mentioned previously, there is a general sense that the outer environment is toxic and hostile and that body boundaries are vulnerable to these threats to health. There is a kind of fluidity between the outside environment and the body, but there is a protection against dangers: the immune system. The immune system is seen as a central organising feature of most of these new illnesses. The past decade has witnessed the immune system gathering increased prominence in public discourse about health. It is generally believed to be weakened by modern stresses, food and pollutants. The relative strength of the immune system is popularly seen as providing the key to avoiding many illnesses. Themes of bodily vulnerability in the face of ever-present risk are at the heart of CFS, MCS and other new illness discourses. Similarly, GWS shares with other new illnesses the central notion of overload or over-challenged in the face of twenty-first-century life. The immune system giving way under the strains of modern living is central to CFS and MCS theories of illness.

The emphasis in immunology is on flexibility and adaptability, but veterans suggest that their body was in the end unable to respond to the sheer demands of flexibility upon it. When veterans refer to their immune system as damaged and degraded they are also talking about their position in the world. Different illnesses, symptoms and experiences can be brought together by way of the immune system and defined as a single disease category. Each person is seen as an individual, yet the social and community aspect of the illness remain central. The immune system provides an inclusive and flexible system which can incorporate infinite variations.

Dumit (2000, 2006) suggests contested illnesses such as GWS and CFS are causally undetermined: their aetiology is contested as to social, genetic, toxic and personal possibilities. Although their nature is contested, sufferers and advocates maintain an unflinching conviction

as to their nature. As was discussed in Chapter 5, the GWS movement is characterised by a vehement denial that sufferer's physical distress arises out of PTSD or other psychological problems. GWS shares with other new illness movements a reliance on biological explanation and a vehement drive to prove the biological, physical nature of the illness. Despite the increasing use of psychological explanations in popular discourse, it is clear that psychological illness and distress remain highly stigmatised. This stigma is associated with the bias in biomedicine, which continues to perpetuate a dichotomy between mind and body: illnesses are seen to arise from one or the other. Importantly, physical illness is treated as more real and important, whilst psychological illness is seen as imaginary. Medicalisation is instigated by the sufferers themselves, but it is a particular kind of medicalisation, linked to the strong anti-psychiatry position of these illness movements.

In keeping with their conviction that their illness is physical, sufferers focus on the tools of medical science to uncover its mystery. These illness movements are characterised by analogies of struggle and injustice. CFS and GWS literature remains highly critical of medicine and doctors, but it also espouses an extreme faith in the absolute success of medical science in unlocking the enigma of GWS. Shorter notes that physicians are frequently described as "heartless ignoramuses, blinkered in the cul-de-sac of mainline medicine" (1995: 117). In the GWS movement, doctors and scientists are valorised as excellent if their conclusions support the cause, yet demonised if they refute the presence of GWS. Doctors, however, remain the gatekeepers and veterans maintain an adamant belief in the power of medicine. Such movements attack medical authority at the same time as they desire its approval (Aronwitz 1992). Thus, veterans demand more and more tests in the belief that one such test will eventually reveal the physical nature and cause of their suffering. They demand to be the object of medical science. In discussing these new illnesses, Dumit (2006) argues that they arise as they do out of a situation where suffering has been collapsed onto medical care. If you are suffering, then you are in need of medical care, "if you then can't get medical care or insurance or disability, then there is an assumption that you probably aren't really sick and you probably aren't really suffering [...] It points, perhaps, to a cultural situation where we have become dependent on the verification of suffering by third-parties" (2006: 585).

## The Medicalisation of Life

The “progressive medicalization of daily life has brought unrealistic expectations of cure that make untreatable infirmities and unavoidable ailments seem even worse” (Barsky 1988: 414). In writing about the increase in medically unexplained syndromes, Barsky and Borus (1995) suggest that the processes of somatisation and medicalisation reinforce one another. The tendency to conceptualise medical problems in biological terms is powerful, making medical practitioners often reluctant to explore the non-biological aspects of a patient’s case. Patients respond to the cues offered by health professionals and are themselves part of a culture that continues to stigmatise mentally ill people and those with emotional problems.

As a result of this “potential stigma, patients are naturally eager to avoid psychiatric labeling and seek a medical or other external, environmental explanation for their distress” (Kirmayer 1999: 274). In addition, they use a variety of strategies to avoid psychiatric labelling. Cultural idioms of distress may make specific somatic symptoms or illness attributions highly salient and, in conjunction with the widespread stigmatisation of emotional conflict and psychiatric illness, lead individuals to de-emphasise or suppress the emotional component of their distress to avoid psychological attributions (Fabrega 1991). The structure of the health care system plays an important role in defining which symptoms or problems are appropriate to take to a doctor – who in most places is likely to be a primary care provider with limited time for, or interest in, non-organic problems.

Patients with medically unexplained somatic syndromes are often convinced that they have a specific occult disease and therefore arrive in the physician’s office with an explanatory model for their symptom: a self-diagnosis (Stewart 1990). The process of labelling themselves often involves communication with other sufferers, Internet searches or media stories. Others “are apparently re-labeling preexisting bodily distress as a disease and seeking medical attention because of this new cognitive understanding of an old symptom. Thus, medicalisation stimulates somatisation by amplifying pre-existing, benign discomfort, supplying a new disease attribution for it, and ushering these individuals into the medical care system” (Barsky and Borus 1995: 1932).

Most often within the medical system, sufferers of these medically unexplained conditions are thought to be somatising. The medical reading of somatising patients is that they are attributing bodily complaints assumed to arise from psychological disturbance to organic disease (Bass and Murphy 1996: 103). Somatisation is the propensity to experience and report somatic symptoms that have no

pathophysiological explanation, to misattribute them to disease and to seek medical attention for them (Lipowski 1988: 1358–68). Generally, then, somatisation in psychiatry or medicine is seen as the expression of psychological or emotional problems in terms of bodily complaints. Goldberg and Bridges (1988), for example, argue that somatisation is a route through which people unsympathetic to psychological illness can enter the sick role while psychologically distressed. Importantly, a diagnosis of somatisation is often slightly derogatory in that it implies the patient is not being truthful or, at the very least, is unaware of the real nature of their problems. The diagnosis often accompanies assumptions about the sufferer not being intellectually sophisticated or being unwilling to accept psychological explanations. GWS is often described as a somatisation condition; a discussion of somatisation has dominated the GWS debate, with veterans strongly denying this explanation.

## **The Approach of Anthropology**

Anthropologists have struggled with the notion of somatisation – a struggle which is largely due to the explanatory power the theory of somatisation holds. As Trimble (1982) has pointed out, the term “somatisation” is now used indiscriminately in patients’ notes as if it were an end to the diagnostic process. Its use assumes that everyone, except the patient, understands what the cause is of the symptoms. The word is doubly unfortunate because it not only suggests a unitary aetiology where none exists, but also perpetuates the “either/or”, “organic versus psychological” dichotomy in medicine (Bass 1990). Somatisation is used as though it is an explanation in and of itself. It often represents the end of the search for explanation. Furthermore, anthropologists try to avoid the implication that somatisation is a psychological process, but this is often difficult. This book shows that concluding that GWS is somatisation is simply not good enough. Instead, one must examine the specifics and the way in which GWS is an expression of particular experiences.

### *Anthropology and Somatisation*

As a result of the mind–body dualism that pervades medicine, any bodily expressions of emotional distress have been attributed to the specific psychological mechanism of “somatization” (Kirmayer and Robbins 1991). There are a number of problems with the medical

interpretation of these contested illnesses as a form of somatisation. It does exactly what veterans and sufferers of similar illnesses are trying to avoid: define the illness as psychological. It simply does not resonate with their experience and does not enable them to make sense of it.

Kleinman and Kleinman (1985) noted, from the cross-cultural perspective, it is not somatisation but psychologisation in the West that appears unusual and requires explanation. The term “somatisation”, turns the “ambiguity and uncertainty of medically unexplained symptoms into the presumptive clarity of a distinct form of psychopathology” (Kirmayer 1999: 272). Kirmayer suggests that any “serious analysis of the problem should probably begin by reversing this rhetorical move and turning ‘somatisation’ back into its ‘raw observable’: medically unexplained symptoms” (1999: 272). When reduced simply to symptoms of a disorder, the meaningful and social dimension of distress may be lost (Kirmayer 1999). This book has presented another approach to GWS by paying heed to the symptoms themselves and the symptom-reporting in context in order to bring the social dimensions back into the equation. Instead of seeing symptoms as mere biological entities, I have focused on the meaning they communicate. The focus has been on the sufferers’ accounts, the symptoms themselves and the context within which we find them, in order to understand what was being expressed and commented upon better. I focus on the “raw observable”, the symptoms and explanatory models themselves, to understand the meaning they may be conveying better.

Scheper-Hughes and Lock (1987: 30) have called for a major theoretical synthesis: “the development of a new epistemology and metaphysics of the mindful body and of the emotional, social, and political sources of illness and healing”. Somatic symptoms have been variously described as “communicative acts” (Kirmayer 1984) and “coded messages” (Racy 1980), whereby the individual, having troubles in various areas of life, conveys these in bodily terms. That is to say, physical symptoms can be seen as part of a process of making meaning out of experience. This idiomatic use of symptoms “allows people to draw attention to – and metaphorically comment on – the nature of their quandary” (Kirmayer 1996: 3). As Obeyesekere (1981, 1990) argues, culture allows individuals to appropriate these collective symbols to work with personal conflict. At the same time, culture works through individuals as each person contributes to new collective meanings through their own symbolic constructions. Political and personal problems are both problematised in and expressed through the body: what Turner (1996) calls “somatic society”. GWS can be interpreted as a personal and social expression of the concerns and experiences of those it affects. The body is a site of angst and resistance.

GWS can be interpreted as the expression of a collective social angst and is a kind of shared bodily language, an expression of social distress as well as a form of commentary. It is both personal and social. Part of this book focuses on the symptoms themselves in order to understand what they may be expressing.

Illness behaviour “in acute or subacute somatization may become prolonged and eventually frozen into a long-term sick role in which complaining about bodily symptoms and preoccupation with illness form a central part of one’s everyday behaviour and means of dealing with other people, as in chronic pain syndrome” (Kleinman and Kleinman 1985: 473). Alternatively, “chronic somatization sometimes occurs in the absence of any medical or psychiatric disorder as a habitual coping style or idiom of distress” (ibid.). Altered social relationships and economic benefits are the “social gains” that reinforce psychobiological processes and maintain illness behaviour in the ways described.

Conversion symptoms can be understood as protests of the powerless against intolerable social circumstances (Weller 1988). In her research into CFS, Ware (1993) found that accounts given by the interviewees of their lives in the months or years before the onset of CFS overflow with references to how active, how busy, how involved in *life* they were at the time and how difficult they found it to say “no”. The result, she argued, is a kind of “cult of busyness” (Salzman 1991), an exhausting lifestyle brought on, as one individual put it, by “overdoing, overworking, over-trying-to-please-everybody, and just doing everything”. Similarly, I would argue that GWS can be seen as a form of protest. The life histories Ware recorded contain evidence of considerable distress: “negative life events in the form of serious injury, divorce, job loss, and/or death of a family member or close friend were reported as occurring before the onset of CFS by a large proportion of the sample” (Ware 1993: 65). In the same way, GWS sufferers often report a series of negative life events which are then re-interpreted and organised together in terms of their connection to GWS.

Abbey and Garfinkel (1991) have noted the parallels between the rapid social change and increasing life pace that surrounded the rise of neurasthenia in nineteenth-century US society and the emergence of CFS in recent years. Ware’s work (1993) contributes to such a reading by showing that there appears to be an empirical association between CFS and a stressful, fast-paced lifestyle. Her research further suggests that people who develop CFS may oversubscribe to such a notion of constant exhaustion as a way of life. GWS could be interpreted in a similar way: sufferers oversubscribe to the notion of success as physical excellence, fitness and masculinity. Anthropologists have argued that physical bodies are shaped by culture, partly by means of widely held

models, images and metaphors. What is considered a “normal” or “healthy” body is a cultural process. Metaphor not only arises out of embodied experience but, conversely, becomes embodied (Kirmayer 1992). Thus we should investigate “the psychophysiology of metaphor” (1992: 336). In a discussion which connects immune systems, health, psychology and culture, researchers have suggested that cultural dissonance may be enacted somatically (see Wilce 2003). When the “individual is continuously checking his or her own cultural consonance and finds it wanting, it is likely to be a frustrating and depressing circumstance. This is a process that is also expressed somatically” (Dressler et al. 1998: 440 in Wilce and Price 2003).<sup>1</sup> GWS can be seen as a somatic expression of falling short of military and societal ideals.

Science treats “the gray or fuzzy facts as if they were the black-white facts of math” even though no one has ever found a single fact about the world that was 100 per cent true or 100 per cent false (Kosko 1994: xv). Yet in our language, science, mathematics, logic and culture we have assumed a world of black and whites. As Bertrand Russel (1972) said, everything is vague to a degree you do not realise until you have tried to make it precise. In an attempt to move away from traditional thinking which forces illnesses into the “either or” category, this work has used a more anthropological approach. There is a need to see illnesses not as either psychiatric or physical, but to complicate and contextualise by introducing the social and the cultural forces which help to produce such illnesses. By showing illness in context we are able to see that GWS and other contested illnesses cannot be fully understood by explaining them as a form of somatising: of expressing psychological distress by way of physical symptoms. Nor is it helpful to suggest that they are the result of purely biological processes. Instead, we should see illness as a way to express and talk about issues relevant to those it affects.

Illness and discussions about illness are a means to work out and make sense of life’s conundrums. Furthermore, anthropologists draw attention to the more collective aspect of symptoms and symptom language. Anthropologists look at these illnesses as examples of “idioms

1. So, for example, one of the few somatic interpretations of culture-bound syndromes – Balinese pregnancy with stones (Wikan 1990) – could be interpreted as a failure to live up to Balinese ideals (Wilce and Price 2003). A flat stomach represents discipline and self-control; in contrast, the bloated stomach is the very image of the failure to meet standards of hard work and self-denial. The abdomen “becomes the site in which Balinese might involuntarily be made to embody status-conflict and social tensions” (Wilce and Price 2003: 64).



of distress" (Nichter 1981) and point out that somatic symptoms are the most common expression of social problems and emotional distress (Kirmayer and Young 1988). In anthropology, illnesses are seen as an organising feature, a way to make sense of life events and distress.

### *Interpreting Somatic Symptoms*

An anthropological reading of GWS looks at the way in which it is wider than issues contained in the Gulf War. Illness symptoms can be read as "coded metaphors that speak to the contradictory aspects of social life, expressing the feelings, sentiments, and ideas that must otherwise be kept hidden" (Scheper-Hughes and Lock 1986: 138–39). Somatising metaphors are often the way that distress is expressed. The "individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity, and struggle" (Scheper-Hughes and Lock 1987: 31). We can interpret GWS symptom-reporting as a vehicle to draw attention to and a means to communicate concerns of the people it affects: issues such as trust, life within a dramatically changing military, gender roles and toxicity. GWS can be interpreted as an expression, both social and personal, of the life-worlds of those it affects and of contemporary issues.

It is necessary to acknowledge that GWS shares many characteristics with other emergent illnesses. By looking at the wider context we can shed light on GWS. However, there is a danger of generalising. Lumping all of these illnesses (GWS, MCS, IBS, CFS) together as one phenomenon results in the erroneous suggestion that they are interchangeable and are the expressions of the same experiences. By grouping them together as manifestations of the same thing the way each of these conditions is unique and responds to different issues is ignored. Such an analysis overlooks the differences between these very diverse illnesses and by so doing lacks a real understanding of the conditions themselves and the unique factors which give rise to them.

This book is a response to the attempt to explain GWS through generalising. Although I think it necessary to contextualise GWS through situating amongst its sister illnesses, this must not be the end of the process of explanation. Instead, more is needed. This book focuses on this additional perspective and has shown the need to bring back the specific. If we take GWS as a real illness and take the individual suffering of the veterans as real, then the particular must be examined. It is for this reason that I have approached GWS from the perspective of anthropology. An anthropological approach is important

to the study of this illness because it enables one to explore the nuances and subtleties which are so central to the illness: it is these complexities that make the illness unique. The illness may not be specific in the medical discourse, but for the anthropologist the particulars are central.

GWS is reflective of the culture in which it is found: both that of military culture and the wider culture of twentieth-first century Britain. As a mechanism to make sense of life events and misfortunes of a specific group, this illness, however, is unique. It responds to and expresses issues of contagion and loss of masculinity which dominated these veteran's experience. Issues of confidence in authority, gender roles, blurred boundaries, notions of trust and the ideas of conspiracy are significant themes emerging from GWS narratives – fed by veterans' experiences of a changing military and of the war itself. By studying GWS and the lives of those it affects social concerns and anxieties are illuminated.

## **Ethical Issues and Dilemmas**

As I wrote this book I grappled with ethical issues. In many ways ethical dilemmas are central to this work and the matter of moral values and principles can be felt on many levels (see also Chapter 2). As a result of space limitations, I am unable to effectively expand on and do justice to the ethical issues raised by this work, instead, in this section I will concern myself with the most important whilst developing a fuller discussion in a forthcoming paper.

Readers will note that I have decided to use pseudonyms for veterans, their family members and the veterans' association, while I did not disguise the identities of most of the organisations, medics and scientists. Unfortunately, this reproduces and highlights the distinctions between these two groups. By so doing am I not implying that the veterans are more vulnerable or in need of anonymity? Perhaps some would suggest that this distinction has ramifications for claims to authority and knowledge.

It does, indeed, seem to establish an unfortunate distinction between those who are robust enough to be identified and those who are not.<sup>2</sup> It could be interpreted that those who are named are considered to be more authoritative and, thus, supported by the book more generally.

2. I am grateful to Dr Simon Cohn for this helpful discussion about issues of anonymity and claims to knowledge.

However, I would argue that this is entirely untrue. My decision to use pseudonyms for the veterans but not medics and scientists is twofold. The first of these is to do with logistics: the scientists I met were well known in the community as were their theories and body of work. All had published in various journals or had made their work widely available and, thus, their work and their ideas were in the public domain. This meant that it was near impossible to afford scientists and medics anonymity. It can be argued that veterans' theories and personal accounts were also in the public domain as many had appeared in media stories. However, not all had spoken publicly, making it far easier to provide anonymity in their case. The second reason revolves around the issue of robustness and vulnerability. It is not that I am implying that the veterans' accounts, experiences and theories do not hold up to scrutiny or that they need protecting from them, but instead that they have more to lose. Importantly, it is not that I may have to protect them from their own words, but possibly my interpretation of those words and actions.

When asked what I was researching, the first question immediately fired at me was, "so, does it exist?" I came to expect such questioning from non-academic acquaintances; yet I was also to hear this phrase repeatedly from doctors, scientists, academics and, interestingly, from colleagues within anthropology. Often when I presented my work other anthropologists would invariably want to focus on physical evidence. It became clear that colleagues felt that the only way appropriately to represent and give the veterans "a voice" was to suggest that their illness was, in fact, "real". "Real" meant that it was a physical and discrete biomedical phenomenon; one can see the assumptions wrapped up in this distinction.

"Does it exist?" "Is it real?" These are the big questions. Real illness means the veterans are telling the truth, they are truly (physically) suffering, the illness has been caused by an external physical agent. This, in turn, means that the government is responsible, that they were poisoned, which denotes cover-up and conspiracy. All of these factors are linked. "No, it doesn't exist" means the veterans are either lying or exaggerating their illness; they are the victims of stress and/or are merely trying to get compensation. It is one or the other. I soon realised how widespread the ideas of government conspiracy and cover-up are – as are fears of poisons, toxins and chemicals. My academic colleagues were quick to believe that the government is an evil conspirator and these poor veterans had been caught up in their game.

We social scientists must also ask who is the audience and whose voices are we to represent? The sufferers of GWS, yes, but I also must acknowledge all of the sufferers – those that want to remain quiet as

well as those who wish to bang their fists. The GWS community, however, includes more voices: there are scientists, healthy veterans and veterans who do not have GWS, but are ill. The AAA 1971 Principles of Professional Responsibility says that “anthropologists bear a positive responsibility to speak out publicly, both individually and collectively, on what they know and what they believe as a result of their professional expertise”. Furthermore, we anthropologists bear a “professional responsibility to contribute to an ‘adequate definition of reality’ upon which public opinion and public policy may be based” (AAA 1971: clause 2d in Caplan 2003: 21). We must unmask the taken-for-granted discourse by listening to all parties not simplistic explanations. I hope that this book does this.

During the writing of this book I worried about the way the information and interpretations contained within it would be received by various parties. How would the sufferers react to the portrayal of their accounts of the illness? Would they disagree or feel betrayed? Worse still, could this book be used to de-legitimize or dismiss veterans’ appeals to be heard and compensated for their illness? Studies focusing on the social construction of phenomena must take into account the problems social examinations pose for the entities they study. The problem is that social and cultural examinations of problems, and particularly contested illnesses, at times seem to explain the problem away and are more useful to the critics than the proponents. Bammer and Martin’s research into the Repetitive Strain Injury (RSI) movement found the “sociology of medical knowledge, with its symmetrical analysis of negotiations over knowledge claims, selectively aids the critics of RSI. This is because, under the circumstance of the debate, deconstructing knowledge claims undermines to a greater extent the position that RSI is a real, organic condition” (1992: 230). Research which pointed out the social causal factors of RSI were used to imply it was not a true, organic medical condition. Social constructionist perspectives helped to dismantle the case for RSI being a “real” biomedical disorder by undermining the significance of efforts of RSI proponents to wield scientific methods to prove its existence (Bammer and Martin 1992).

Researchers must be aware that their findings may contribute to the debate at hand and, as Bammer and Martin (1992) suggest, one’s approach cannot remain non-partisan. As an anthropologist, my focus is on the social and cultural factors of GWS and by the very nature of the approach I am suggesting that there is more to this illness than pure organic causes and symptoms. For a medical anthropologist this is self evident, yet for those reading my work this could be seen as harmful in itself. For, it goes against what the veterans are struggling to have

acknowledged. Whether it is intended or not, one's work may be taken up by advocates in the debate being studied. A range of claim-makers may try to "capture" analysts to serve their own purpose (Bammer and Martin 1992). This process of attempted capture cannot be avoided by the analyst and undermines claims to neutrality (Scott et al. 1990; Hess 1993 in Bammer and Martin 1992). Bammer and Martin conclude that it is futile to attempt to eliminate partisanship "de facto or otherwise. Instead, a plurality of partisanship should be encouraged, in the spirit of the maxim that 'there is no single road to truth'" (1992: 231). As anthropologists, then, we must be aware of how our findings are being received and made use of by interested communities and institutions. How does one manage this use of one's research findings? Although one cannot be in control of those who use one's work inappropriately, one has an obligation to maintain a presence in the debate and provide ongoing input into the findings and their uses.

Of course I also thought about my informants and their reactions to the work, if they were to read it. How will they feel about what was written in these pages? How would Steve, who drank to forget his memories and his worry about dying and leaving his young daughters alone, feel if and when he read this book? Would my findings negatively impact on Bob, who would once again be going before the War Pensions Tribunal for his impotence, marriage problems, fatigue and anger? Over this I struggled, but the interpretation contained in these pages is that: an interpretation. It is my rendering based on what I heard and observed during my fieldwork. In a sense, just as they created narratives to make sense of their experiences and sense of disruption, I created this narrative: the account is my attempt to make sense of their stories. It is not meant to be a definitive explanation of the illness, but instead an additional perspective to add to those already being put forward. Importantly, I am now in the process of discussing these findings with the veteran community and a joint publication or a publication based on their reactions to this work is planned. I feel it is important for informants to have an opportunity to discuss and have input into my work, but I wanted this book to be the start of this process.

Importantly, this book is meant to be a descriptive and qualitative account to balance the previous focus on medical and epidemiological data; it is meant to provide additional data and interpretations to a subject which has often been contained within the gate-keeping mechanisms of medicine and epidemiology. Despite problems with postmodernism and its position on ethics, their preference for a cacophony of voices (Kuper 1996 in Caplan 2003: 13) is helpful to consider here. The ethnographic object as multifaceted, only available

to be glimpsed momentarily and incompletely, is a useful way of conceptualising my subject. I think it helpful to think of ethnography as providing another perspective to the plethora of perceptions and truths: “there could be no single, true, objective account of a cultural event or a social process” (Kuper 1996: 188 in Caplan 2003).

What does one do if the people one is studying disagree with the interpretation one is presenting? More worryingly, what happens when one’s informants feel as though they have been betrayed by one’s findings? In his work based on his fieldwork in a Genetic Counselling Clinic, Bosk (1992; 2001) was faced with such feelings of betrayal on the part of his informants when both the surgeons and the genetic counsellors felt misrepresented by his book. This sense of betrayal, however, did not centre on the accuracy of his description or the incidents themselves, but on the context within which he placed the description of incidents. Thus, they disagreed with and were angered by his *interpretation*. Bosk responds by noting that: “but the interpretation was, rightly or wrongly, for better or worse, mine” (2001: 211). Similarly, I hope that those represented in this book will agree with most of the content, as I have tried to depict GWS illness models and theories of causation as fully and as accurately as possible. It is where I introduce a more interpretative approach that I worry informants may disagree with the analysis. The very nature of the way in which we are trained to think as anthropologists means we are likely to conclude in ways with which our informants do not agree.

Akeroyd (1984 in Caplan 2003) suggests anthropologists should aim to achieve some sort of balance in responsibility towards different parties: subjects of research, colleagues, funding bodies and gatekeepers. Caplan (2003) points out that Barnes also suggested that the intrinsic characteristic of social research is intellectual and social compromise. The “competent fieldworker is he or she who learns to live with an uneasy conscience but continues to be worried by it” (Barnes in Akroyd 1984: 184). Barnes’ insight about the nature of fieldwork rings very true in my experience. An ethnographer often walks an uneasy line and is sometimes forced to dwell in the grey areas of ethics. I was often paralysed by worries and fear of acting unethically. Although I did not enjoy those moments, I am pleased I had them as it meant that I was acutely aware of the ethical dilemma involved in my work: an experience most anthropologists will recognise. It is vital that we be aware of the need to strike a balance between protecting informants and feeling free to analyse and produce work that is academically rigorous.

I am convinced of the distress of sufferers and the way it is felt in their joints, their stomachs and the rest of their bodies, but I believe

such suffering is added to significantly by their feelings of being ignored and dismissed. Part of their suffering arises out of the way they have chosen or been forced to think of, experience and frame their illness. Focusing on the physical cause and physical nature of their disorder contributes to their frustration – a result of the way the GWS debate has been constructed along the lines of the physical versus psychological dichotomy in biomedicine. This book contends that we all, veterans included, must think beyond such mind–body dualism in order for any real progress to be made. In this book I offer an additional perspective to the GWS discourse and provide a remedy to the generalising trend in the present discourse. I provide an in-depth portrayal of GWS narratives and explanatory models in order to gain a better understanding of how GWS is lived and felt by those it affects.

## **Conclusions**

These men and women are ill and suffering; of this I have no doubt. I hope the reader will take away from this work the very real sense of the distress of these people. Their bodies ache, they are constantly fatigued and life feels like a constant struggle. Memories evade them. Their lives have been irreducibly damaged. Their children are growing up with fathers who cannot get off the couch to play with them. Wives complain that their men are impotent, irritable shells of their former selves. They simply are not the men they were. Yet despite the weakness they exhibit and express, they are angry. Frustration and anger are a constant presence in their lives. Fierce words are exchanged: the MoD is a malevolent force who purposely poisoned them; doctors and scientists are deceitful liars; and the general public do not care. Sometimes the rage is frightening.

What makes a discussion of GWS so compelling is that the suffering continues. Veterans are still suffering and their struggle for recognition continues. News stories about GWS are still common occurrences, reflecting the continued public interest and investment in the subject. Of course, a discussion of combat-related illness is particularly relevant as we continue to send troops to Iraq and Afghanistan and wait to see the impact of combat on those soldiers. GWS is an illness still being constructed and moulded as it incorporates contemporary issues as they surface. Thus, I have read accounts of people who believe they are suffering from GWS as a result of the September 11 2001 attacks on New York: “post-WTC syndrome”. GWS is a vehicle to discuss and convey cultural anxieties and beliefs.,

GWS seems to be a stone which has been tossed into a pool of water, sending ripples out to infinity. It is a reflection of wider social trends, assumptions and anxieties which seem to resonate with no end in sight. The boundaries of GWS have a way of expanding outwards. The concerns of Jack, the TA squaddie who was a chef in the Gulf War, resonate with the fears of Beth, a navy pilot who was recently deployed to Iraq. However, the experiences extend even further than veterans and other military personnel. Jack's experience of GWS reach the mother who is worried about whether or not to give the MMR to her 18 month daughter and the young man who is concerned that toxins may be causing him to have allergies to more and more things. The boundaries keep being extended.

Veterans are expressing very real distress and they are doing so through their bodies. Their symptoms are a kind of language. For, "sickness is not just an isolated event, not an unfortunate brush with nature. It is a form of communication through which nature, society and culture speak spontaneously" (Scheper-Hughes and Lock 1987: 31). Veterans are embodying their experience of being redundant and being unmanned. Their symptoms and the way they talk about them suggest that their bodies are making sense of the experience of falling short of an idealised and structured masculinity.

It is crucial that illnesses like GWS be better understood in order to move towards a phase of recovery for the veterans. This is particularly relevant as we are now facing the almost inevitable beginnings of a related illness which will emerge from the ongoing conflict in Iraq and Afghanistan. Indeed, as I write the soldiers of that conflict have come forward complaining of physical and psychological symptoms. It seems inevitable that we will see some form of post-combat syndrome, but what form it will take remains to be seen. GWS represents a range of changes to previous combat syndromes which will likely become greater and more applicable to an ever-widening group of people. Given the present milieu with increasingly blurred boundaries between civilian and military, war and peace, with its accompanying anxiety about terrorism, it is likely that the template of post-combat syndromes will be increasingly accessed to make sense of illness experiences.

We can interpret GWS symptom reporting as a vehicle to draw attention to and a means to communicate concerns of the people it affects: issues such as trust, life within a dramatically changing military, gender roles and toxicity. GWS can be interpreted as an expression, both social and personal, of the world of shared social meanings in which veterans live and interact, and of contemporary issues.



## Appendix One

### **SYMPTOM LIST**

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Chronic Fatigue Syndrome	Paralysis of eye muscle	Poor hygiene
Irritable Bowel Syndrome	Paralysis of face muscle	Violence
Multiple Chemical Sensitivity	Glandular swelling	Blackouts
Fibromyalgia	Sensitivity to sunlight	Poor co-ordination
Headache	Nose bleeds	Clumsiness
Frequent urination	Tiredness/fatigue	Nightmares
Difficulty in urinating	Bad sleep patterns	Irritability
Joint swelling	Low libido	Mood swings
Joint pains	Abnormal blood tests	Loss of appetite
Cracking joints	Palpitations	Anxiety
Muscular pain	Pains in tendons	Stress
Pins and needles in fingers/toes	Sinus problems	Paranoia
Bleeding gums	Spinal disk disease	Depression
Rashes	Hair loss	Agoraphobia
Ulcers	Kidney disease	Lack of self-esteem

Constipation	Deafness	Lack of confidence
Diarrhoea	Menstrual problems	Adultery
Stomach pains/ problems	Vaginal cancer	Marriage problems
Memory loss	Cancer	Criminal activity
Miscarriage	Burning Semen Syndrome	Substance abuse
Birth deformities	Thrush	Feelings of déjà vu
Persistent infections	Viral illness	Lack of motivation
Abnormal liver function test	Sickness	Lack of concentration
Asthma	Dizzy spells	Poor self- awareness
Chest pain	Motor neurone disease	Night sweats
Respiratory problems	Bad eyesight	Short temper
Weight loss	Epilepsy	
Weight gain	Feelings of loss of time	

**Source:** Information sheets from Gulf veterans' associations<sup>1</sup>

1. Presented in the order outlined in veterans' association information sheets.

## Appendix Two

### **VETERANS INTERVIEWED (67): BRANCH OF SERVICE**

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Army	57
RAF	3
Navy	6
Civilian	1

**Figure 3: Informants' Branch of Service**

#### **HEALTH STATUS OF THOSE INTERVIEWED (67)**

Not ill <sup>1</sup>	19
Ill but not with GWS	3
GWS sufferers	45

1. Includes people who have some symptoms, but do not consider themselves as "ill" or having GWS. May have some symptoms that they think may have been caused by Gulf, but are unsure.

**JOB WHILST IN THE GULF WAR** (38 of 45 sufferers listed job)**Non-deployed** **7****Support services** **26**

medical (nurse, operating technician) 11

chef 2

other (clerk, driver) 11

aircrew 2

**Combat support (i.e. engineer)** **2****Combat (“Teeth”)** **3**

infantry 2

cavalry 1

## Appendix Three

# **PROGRAMME OF ROUTINE TESTS UNDERTAKEN AT THE GVMAP**

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Full Blood Count

**Blood Chemistry Tests:**

Urea, Electrolytes, Creatinine and Proteins  
Liver Function  
Thyroid Function  
Serum Calcium, Phosphate and Alkaline Phosphatase  
C Reactive Protein  
Sugar (Glucose)

**Other tests for:**

Borrelia  
Hepatitis B  
Hepatitis C  
Urine analysis  
Electrocardiography  
Abdominal Ultrasonography  
Peak Air Flow

Source: MoD website, [http://www.mod.uk/issues/gulfwar/map/routine\\_tests.htm](http://www.mod.uk/issues/gulfwar/map/routine_tests.htm)



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# INDEX

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- Abbey, S. and Garfinkel, P., 220  
Abou-Donia, M.B. et al., 29  
Abou-Donia, Mohammed, 30, 84, 156  
Abu-Qare, A.W. et al., 29  
adultery, 58, 232  
age, exposures and, 99–100  
Agent Orange, 88, 170–71, 205, 206  
agoraphobia, 231  
Agostino, K., 180, 185, 186, 189, 198, 200  
AIDS, 94, 97, 161, 163, 168  
Akeroyd, A.V., 227  
Anderson, I. et al., 202  
anthropology  
    approach to GWS of, 218–23  
    balance in responsibility, aim of, 227  
    behaviour, intelligibility of, 8–9  
    causation, levels of, 55  
    cultural shaping, 10–11  
    focus of, 5–6  
    moral universes in, 8–9  
    Principles of Professional Responsibility, 225  
    special contribution to study of GWS, 11–12  
    western science, challenge to, 51–2  
anxiety, 24, 25, 26, 28, 44, 231  
    blood tests, 78  
    bodily substances, mixing of, 78  
    body frontiers, 93, 105, 181  
    depleted uranium, 170  
    depression and, 30  
    gender anxiety, 196–8  
    health, 4, 39, 212  
    impotency, 182  
    orifices, 91  
    risk and, 2  
    semen, 181, 182  
    sex and reproduction, 156  
    social change, 30, 214  
    terrorism, 229  
    vaccinations, 108, 212  
appetite loss, 231  
Araneta, M.R.G. et al., 164  
Aristotle, 57, 182  
Arksey, H., 131  
Aronwitz, R., 216  
Aronwitz, R. and Spiro, H., 151  
asthma, 23, 165, 175, 232  
Autism Research Unit, 72  
auto-immune diseases, 72, 77, 85, 99, 112–14, 119, 208  
Azande witchcraft, 11, 18, 55, 56–7, 59, 214  
  
Bakal, D.A., 142  
Baker, Mark, 195n7  
Bammer, G. and Martin, B., 225–6  
Barnes, J.A., 227  
Barrett, F.J., 184, 185, 186–7, 188, 193, 197, 198, 207  
Barsky, A., 39, 133, 139, 214, 217  
Barsky, A. and Borus, J., 39, 214, 215, 217  
Bartlett, F.C., 130

- Bass, C., 218  
 Bass, C. and Murphy, M., 217  
 Bauman, Z., 49  
 Beck, Ulrich, 39–40, 40n20, 43–4, 47, 137, 138–9, 199, 212  
 Becker, G., 126, 128, 137  
 Bernstein, A. et al, 160  
 bias on causes, 50–51  
 biography, self-production of, 137–9  
 biological and physical explanations, advocacy of, 141–52  
 biomedical analysis, 5, 57–8  
 biomedical community, 3, 179  
 biomedical model of suffering, 93  
 biomedical phenomenon, GWS as, 52, 224  
 biomedical position on GWS, 19–20  
 biomedical process, 138  
 biomedical system, 213  
 biomedical understanding of GWS, 18, 19  
 birth defects, 163–72  
   friendly fire metaphor and, 168–9  
 Black, M., 119  
 blackouts, 231  
 bleeding problems, 21, 22, 76, 231  
 blood  
   blood-brain barrier, 83–6  
   blood tests, 76, 77, 78, 163, 231  
   body substances, 75–7  
 Boddy, J., 181  
 bodily boundaries  
   blood-brain barrier, 83–6  
   dormant illness, 90  
   extension of, 82  
   immune system, 94–7  
   internal risks, 87–90  
   leaky bodies, 83–6  
   shifting boundaries, 81  
 body substances, 67–78  
   blood, 75–7  
   bones, 69–70  
   chemical warfare agents, 82  
   as commodity, 77–8  
   depleted uranium (DU), 68, 69–70, 71, 73, 75, 83  
   diarrhoea, 70–72  
   faeces, 70–73  
   internal surfaces, 68  
   NAPS and, 70, 73, 81, 83–4  
   permeability theory of, 84–5  
   semen, 1, 67, 83, 92, 155–72, 175, 177, 181–2, 183–4  
   skin, 67–8  
   spit, 67, 77, 91  
   sweat, 67, 73, 77, 86, 89, 92, 128, 185  
   toxicity of, 67  
   urine, 73–4  
 bones, 69–70  
 Booth, R. and Divison, K., 120  
 Bosk, C., 227  
 Bourke, J., 184, 187, 189, 195, 196, 203, 207  
 bowel problems, 3, 25, 70–73, 74, 83, 137, 165, 166  
   *see also* Irritable Bowel Syndrome (IBS)  
 Brown, P. et al., 141  
 Burning Semen Syndrome (BSS), 5, 66, 158–62, 169, 182, 232  
 Bury, M., 126  
 Busby, C., 34  
 butterfly rash, 155  
 Cain, C., 131  
 cancers, 1, 10, 34, 56, 58, 90, 104, 105, 119, 168  
   colon cancer, 73  
   prostate cancer, 198, 201  
   vaginal cancer, 232  
 Caplan, P., 40n20, 137, 225, 226–7  
 Caputo, Philip, 195n6  
 Carson, Rachel L., 170  
 casomorphin, 85  
 Cassel, E., 126, 129  
 causes of GWS  
   abundance of information on, 44  
   bias on, 50–51  
   causal factors, reports of, 1–2  
   causally undetermined, 215–16  
   causation theories, 17–18  
   immune system and, 97–115, 120–22

- chains of causation, 43–62  
 combination of exposures, 35–9,  
     42, 58–9, 60–61  
 common cause, causation and, 56  
 conspiracy theories, 48, 59, 60–61  
 contested knowledge, 43–51  
 decision-making, exclusion from,  
     54  
 discussion on, 24–39  
 disinformation, 50  
 expertise, systems of, 44–6,  
     49–50, 52–3  
 genetic factors as causal agent, 38  
 immune system and causation  
     theories, 97–115, 120–22  
 inconsistency, 56–7  
 information, systems of, 44–6,  
     47–8  
 knowledge, systems of, 44–6,  
     57–8  
 knowledge networks, creation of,  
     46–7  
 lay-derived themes, 54  
 levels of causation, 55–9  
 media and information, 53  
 meta-narrative, 60–61  
 misinformation, credibility and,  
     50, 54–5  
 moral evaluation, 47  
 nebulosity, 57–8  
 research about, 48–9  
 risk, emphasis on, 44  
 science, specialisations of, 49, 52  
 theories of, accommodating  
     nature of, 58–9  
 truth and knowledge, claims to,  
     51–5  
 Chalder, T. et al., 2, 132  
 chance, risk averseness and, 40–41  
 chemical warfare agents, 1, 17, 31–2,  
     82  
 chemicals, impact of, 18, 27, 34, 42,  
     71, 84, 85, 167, 179, 191, 213,  
     224  
     absorption of chemicals, 110  
     advocacy of chemical  
     explanations, 141–52  
     chemical sensitivity, 68, 88  
     chemical triggers, 90  
     chemicals in the environment, 87,  
     170  
     immune system, production of  
     chemicals by, 113  
     invisible chemicals, 170  
     protective chemicals, 156  
     toxic chemicals, 29–30, 39, 149  
 Chernobyl, aftermath of, 34, 51, 169  
 Cherry, N. et al., 19, 25  
 children contaminated through men,  
     163–72  
 Chronic Fatigue Syndrome (CFS), 3,  
     4, 23, 45, 101, 106, 145, 148,  
     150–51, 162, 163, 213, 215, 216,  
     220, 231  
     *see also* Myalgic Encephalopathy  
     (ME)  
 Claeson, B. et al., 91, 101, 114, 119  
 Clark, R. and Cumley, M., 94  
 Clausewitz, C.V., 190  
 Clements, A. et al., 133  
 clumsiness, 27, 231  
 co-ordination, problems with, 231  
 Cohn, Simon, 41, 55, 56, 57n4,  
     223n2  
 Coker, W.J. et al., 2  
 Coleman, J., 41  
 collective narrative, 130–31  
 Collinson, D., 187  
 commodification of body substances,  
     77–8  
 conception, difficulties in, 164  
 Connell, R.W., 173, 182, 184, 192,  
     198  
 Conrad, P. and Schneider, J., 129  
 conspiracy theories, 48, 59, 60–61  
 constipation, 232  
 contagion, issues of, 169–72  
 contested knowledge, 43–51  
 context (and contextualisation), 9,  
     11–12, 202–6  
 corporatism and risk, 41–2  
 Cowan, D.N. et al., 164  
 criminal behaviour, 58, 232

- cultural constraints on labeling illness, 187–8
- cultural construct, immune system as, 113, 115
- Dandeker, C., 189, 190
- de Groot, G., 189
- de la Billière, Sir Peter, 33n13, 195
- de Sutter, E., 33
- deafness, 167, 232
- decision-making
  - exclusion of participants from, 54
  - on illness (and reality of), 56
  - non-expert knowledge in, 53
  - on risk, social nature of, 39–40
- deformities, 165, 232
- depleted uranium (DU), 1, 17, 27, 32–4
  - body substances and, 68, 69–70, 71, 73, 75, 83
  - exposure to, 171
- depression, 30, 58, 145–7, 149–50, 168, 182, 198, 231
- diarrhoea, 1, 27, 70–72, 181, 232
- diets, alterations in, 89–90  
*see also* gluten-free diets
- DiGiacomo, S., 10
- Dilthey, W., 129
- disinformation, 50
- dizzy spells, 232
- dormant illness, 90, 104–6
- Douglas, M. and Wildavsky, A., 41n21, 213
- Douglas, Mary, 39–40, 40n20, 41, 42, 44, 47, 51, 90–91, 181
- Doyle, P. et al., 164, 170n8
- Dressler, W. et al., 221
- drugs, experimentation with
  - unlicensed preparations, 35–6
- Dumit, J., 137, 138, 152–3, 213, 215, 216
- Durakovic, A., 33n15, 34, 159
- Durkheim, Emile, 9
- Dyer, C. and Bosely, S., 148
- Ebola virus, 105, 168  
*The Economist*, 31
- Ehrenreich, B. and English, D., 184
- Eisenhart, R.W., 195
- Eisler, R.M. and Blalock, J.A., 198
- emotions and masculinity, 174
- Enloe, C., 185
- environmental chemicals, 87–8, 89
- environmental explanations, 213–14
- epilepsy, 232
- Epstein-Barr virus (EBV), 106, 163, 163n2
- Estroff, S., 202
- ethical issues and dilemmas, 223–8
- ethnography of GWS, 12
- Evans-Pritchard, E., 11, 18, 55, 56–7, 59
- experience, making sense of, 11
- experimentation, veterans' belief in use as 'lab rats', 17, 36–7
- expertise, systems of, 44–6, 49–50, 52–3
- eye problems, 66, 111, 231
- eyesight problems, 232
- Fabrega, Jr., H., 217
- face muscle paralysis, 231
- faeces, 70–73
- fatigue, chronic, 3, 23, 45, 131, 147, 163, 165, 185  
*see also* Chronic Fatigue Syndrome (CFS)
- femininity and masculinity, 189  
*see also* women
- Feyerabend, P., 52
- fibromyalgia (FM), 29, 145, 154, 162, 178, 179, 208, 214, 231
- Fienman, I.R., 184
- Firth, R., 8
- fitness and masculinity, 186–7
- Fortun, K., 44, 60, 61
- Foucault, Michel, 137, 155–6
- Franklin, S., 7
- Frazer, J., 18–19
- Friedman, A. et al., 84
- Friendly Fire: Explaining Autoimmune Disease* (Isenberg, D. and Morrow, J.), 112–13

- friendly fire metaphor  
 birth defects and, 168–9  
 immune system fighting against  
 itself, 113–14, 118–20
- Gacksetter, G. et al., 19
- Galen (Claudius Galenus), 182
- Geertz, Clifford, 121
- Gellner, Ernest, 9, 41, 58
- gender anxiety, 196–8
- gendered insult, 186
- genetic factors as causal agent, 38
- genetically modified (GM) foods, 2,  
 88
- genetics and the immune system,  
 102–3
- Giddens, Anthony, 39–40, 40n20,  
 43–4, 49, 137, 138–9, 199
- glandular swelling, 231
- gliadomorphin, 85
- Gluckman, M. and Devons, E., 59
- gluten-free diets, 39, 73, 86, 89, 103
- Goldberg, D. and Bridges, K., 143,  
 218
- Golomb, B., 84
- Good, B., 126
- Grauer, E. et al., 84
- Gray, G.C. and Kang, T.C., 3, 19
- Gulf War (1990–91), UK  
 deployments in, 2
- Gulf War Illnesses Research Unit,  
 143, 143n7
- Gulf War Syndrome (GWS), 209–29  
 AIDS and, 94, 97, 161, 163, 168  
 anthropology, approach of,  
 218–23  
 arenas inhabited by, 7–8  
 biomedical position on, 19–20  
 biomedical understanding of, 18  
 boundaries of, expansion of, 229  
 causal factors, reports of, 1–2  
 causally undetermined, 215–16  
 causation theories, 17–18  
 causes of, discussion on, 24–39  
 chance, risk averseness and, 40–41  
 characterisation of, 8  
 chemical warfare agents, 17, 31–2  
 combination of exposures as cause  
 35–9, 42, 58–9, 60–61  
 continuation of suffering of, 228  
 corporatism and risk, 41–2  
 depleted uranium (DU), 17, 27,  
 32–4  
 distress and suffering of, 228  
 drugs, experimentation with  
 unlicensed preparations, 35–6  
 emergence of, 1–2  
 environmental explanations for,  
 213–14  
 ethical issues and dilemmas, 223–8  
 ethnography of, 12  
 experimentation, veterans' belief  
 in use as 'lab rats', 17, 36–7  
 female sufferers, 180–81  
 and functional somatic  
 syndromes, 214–16  
 genetic factors as causal agent, 38  
 and GWVA, centrality of, 153  
 health and risk, 213–14  
 health scares, 211–12  
 illness of our time?, 209–12  
 and immune system failure, 93–4,  
 120–22  
 individualisation and risk, 39–40  
 infinite ripples from, 229  
 initial indications of problem, 1  
 interpretation of somatic  
 symptoms, 222–3  
 'Khamisayah incident', 31–2  
 making sense of experience, 11  
 and masculinity, disappearance of  
 175–7  
 media attention, 211–12  
 media stories of health scares,  
 210, 211–12  
 medical position on, 4  
 Medical Research Council (MRC)  
 review, 19–20, 25n7, 164  
 medicalisation of life, 217–18  
 MMR vaccine, scare caused by, 212  
 modernity, risk culture, 39  
 morality and risk, 40

- NBC (Nuclear, Biological, Chemical) attack and, 35, 82, 92, 97
- Nerve Agent Pre-Treatment Sets (NAPS), 27–8, 36–7
- new illness movement, 213
- non-exposure factors, 35
- organophosphates, 17, 28–31
- Philosophical Transactions of the Royal Society*, 20
- polarisation of debate on, 3
- polarity of debate on, 143–52
- post-combat illness, similarities to, 3
- power and risk, 41
- reality of, question of, 12–13
- risk, 39–42
- vulnerability and, 212–16
- scientific information, picking and choosing from, 212–13
- scientific view of, 18
- somatic symptoms and, 4
- somatism and anthropology, 218–22
- symptom reporting, attention to, 229
- symptoms, patterns of, 19–20
- theories of, constant change in, 6–7
- tolerance thresholds, decline in, 214
- understanding and recovery, need for, 229
- vaccinations, 17, 27, 39
- vaccine overload, 25–6
- vaccine poisoning, 21–5
- veterans' accounts, sense in, 18–19
- veterans' views, 20–23, 66–7, 125–6
- visibility, 79–80
- vulnerability and risk, 212–16
- World Trade Centre Syndrome, 211–12
- gums bleeding, 21, 76, 231
- Gunner, G. and Knott, H., 202
- Gusterson, H., 82, 190, 191
- GVMAP (Gulf Veterans' Medical Assessment Programme), 6–7, 21, 68, 105, 156, 158, 163, 169
- GWVA (Gulf War Veterans' Association), 65–6, 125–53
- biological and physical explanations, advocacy of, 141–52
- centrality of, 153
- chemical explanations, advocacy of, 141–52
- collective narrative, 130–31
- and construction of GWS narratives, 126–39
- contacts of veterans with, 136–7
- different men, women's identification of veterans as, 140–41
- institutional structures and GWS narratives, 131–2
- linking of health problems, 125–6
- media as vehicle for narrative, 133
- misfortune and failure, narratives of, 130
- narrative fit, 132
- narratives, personal experiences and, 127–33
- patient activism, 152–3
- post-war identity and community, creation of, 133–7
- psychological distress, stigmatisation of, 151–2
- psychological explanations, denial of, 141–52
- self-help, narratives of, 131
- self-production of biography, 137–9
- uncertainty in GWS narratives, 127–9
- war as filter for negativity in narratives, 132
- women, role of, 139–41
- word of mouth, narrative spread and, 132–3
- gynaecological problems, 162
- gynaecomastia, 155

- Hables-Gray, C., 191n2  
 Hacking, I., 9–10, 11, 12  
 hair loss, 231  
 Haley, Robert W., 29–30, 30n9, 31, 32, 49, 59, 80, 119n16, 202  
 Haley, R.W. et al., 29  
 Harraway, Donna, 115, 117  
 Harris, P., 156  
 Hazen, J. and Trefil, R.M., 119  
 headache, 4, 45, 114, 231  
 health  
   and risk, 213–14  
   scars and GWS, 4–5, 211–12  
 Herdt, G.H., 181  
 Herr, Michael, 195n5  
 Hess, D., 226  
 Hesse, M., 119  
 Higate, P. and Hopton, J., 189, 190, 191n2  
 Hill, Major Ian, 100, 100n4  
 HIV, 97, 162, 167, 168  
 Hofstadter, R., 60, 61  
 homosexuality, 186  
 Hooper, Malcolm, 21, 23, 31, 34, 49–50, 65, 69–70, 72–3, 74, 75, 84–6, 89, 106, 114, 120, 144, 154–5, 178  
 hormones, 87  
   hormone problems, 154–5  
 Horton, R., 51–2  
 Hotopf, M. et al., 108  
 Huber, P., 51  
 human rights laws, 189–90  
 Hussein, Saddam, 1, 28, 120  
 Hyden, L., 126  
 hygiene, deficiencies in, 231  
 immune system  
   age, exposures and, 99–100  
   as arbitrator of the psychological, 107, 121  
   auto-immune diseases, 114  
   boundaries and borders, 94–7  
   causation theories and, 97–115, 120–22  
   central to GWS, 106  
   cultural construct, 113, 115  
   dormant illness, 104–6  
   fighting against itself, 113–14, 118–20  
   friendly fire, metaphor of, 113–14, 118–20  
   functioning of, 120–21  
   genetics and the, 102–3  
   GWS and failure of, 93–4, 120–22  
   immunology and threats to, 94, 120–22  
   inactivity of, 96–7  
   military metaphors, 115–20  
   overload, 110–12  
   permeability of bodily boundaries and, 97  
   recognition and understanding, 96  
   saturation, 111  
   self *versus* non-self, 112–15, 121  
   on standby, 103–6  
   unequal nature of systems, 100–102  
   vaccinations, 108–10  
   weakness in, 96  
 immunology, 94, 120–22  
   psychoneuroimmunology, 107  
 impotence, 157–8  
 NAPS and, 157–8  
 individualisation and risk, 39–40  
 infections, 93, 95, 96, 97, 162, 163, 232  
 infertility, 156  
 information  
   abundance of, 44  
   systems of, 44–6, 47–8  
 Ingleby, D., 129  
 Institute of Medicine, 145  
 internal risks, 87–90  
 internal surfaces, 68  
 irritability, 21, 66, 86, 140, 182, 196, 205, 228, 231  
 Irritable Bowel Syndrome (IBS), 3, 4, 70, 86, 148, 178, 231  
 Irwin, A. and Wynne, B., 46  
 Irwin, A. et al., 26, 48  
 Isenberg, D. and Morrow, J., 112–13  
 Ismail, K. and Lewis, G., 3, 19, 215  
 Ismail, K. et al., 19, 147

- Jacobsen, D. and Ziegler, C., 53  
Jadhav, S., 181, 182  
Jamal, G.A. et al., 29  
Jamal, Goran A., 29, 45, 48, 84, 110  
Jaynes, G., 67  
Jeffords, S., 203  
joints, problems with, 3, 20–22, 45, 66, 76, 140, 147, 154, 165, 178, 226, 227–8, 231  
Jones, E., 158, 192, 205  
Jones, E. and Wessely, S., 3, 144n8, 205  
Jones, James, 195n6  
*Journal of the American Medical Association (JAMA)*, 30
- Kaprow, M., 41n21  
Kennedy, D., 196  
'Khamisayah incident', 31–2  
kidney problems, 34, 58, 68, 71–2, 83, 167, 231  
Kilshaw, S., 206  
Kimmel, M., 185, 186, 189  
Kirmayer, L., 4, 10, 11, 128–9, 142, 143, 151, 207, 210, 217, 219, 221  
Kirmayer, L. and Robbins, J.M., 218  
Kirmayer, L. and Young, A., 4, 222  
Kleinman, A., 126  
Kleinman, A. and Kleinman, J., 4, 219, 220  
knowledge  
  contested knowledge, 43–51  
  networks of, creation of, 46–7  
  non-expert knowledge in decision-making, 53  
  systems of, 44–6, 57–8  
  truth and knowledge, claims to, 51–5  
  *see also* information  
Kohn, T. and McKechnie, R., 137  
Kosko, B., 12, 221  
Kuhn, Thomas, 52
- Lakoff, G. and Johnson, M., 9  
*Lancet*, 25, 29, 48  
Lasch, Christopher, 139  
Latour, Bruno, 46  
leaky bodies, 83–6  
leaving the military, 199–202  
Lee, H. and Jones, E., 20  
Lee, Harry, 143, 144, 169, 179  
levels of causation, 55–9  
Lewis, G., 56, 57  
libido, deficiency in, 155, 157–8, 182, 186, 196, 231  
Lipowski, Z., 143, 218  
Littlewood, R., 8, 10, 173, 195  
liver function, 37n17, 58, 68, 75, 232  
Lock, M. and Scheper-Hughes, N., 11  
Lord Lloyd Inquiry (2004), 20n3, 52  
Lupton, D., 44, 47, 137
- McKechnie, R., 46, 47, 54  
McVeigh, Timothy, 202  
Magnetic Resonance Imaging (MRI) scans, 80  
Mailer, Norman, 197  
male lack, embodiment of, 207–8  
Manderson, L., 201  
Marcus, George, 60, 61  
marriage problems, 130, 157, 226, 232  
Marshall, Carole, 67, 67n1  
Martin, E., 7, 46, 94, 95–6, 99, 102, 109–10, 115, 117–18, 120  
Martin, E. et al., 53  
masculinity lost, narratives of, 154–208  
  anticlimax, war as letdown, 195  
  birth defects, 163–72  
  friendly fire metaphor and, 168–9  
  Burning Semen Syndrome (BSS), 158–62, 169  
  children contaminated through men, 163–72  
  conception, difficulties in, 164  
  contagion, issues of, 169–72  
  cultural constraints on labeling illness, 187–8  
  deformities, 165, 232  
  depleted uranium (DU), exposure to, 171  
  diseases of "old women", 177–80  
  emotions and masculinity, 174



- femininity and masculinity, 189  
 fitness and masculinity, 186–7  
 gender anxiety, 196–8  
 gendered insult, 186  
 glamour of war, 195  
 GWS and the disappearance of  
 masculinity, 175–7  
 gynecomastia, 155  
 homosexuality, 186  
 hormone problems, 154–5  
 human rights laws, 189–90  
 impotence, 157–8  
 impotence, NAPS and, 157–8  
 infertility, 156  
 killing and war, 195–6  
 leaving the military, 199–202  
 libido, deficiency in, 155, 157–8,  
 182, 186, 196, 231  
 male lack, embodiment of, 207–8  
 masculinity under threat, 188–96  
 media representation of war, 191  
 militarism and masculinity, 189–90  
 military and masculinity, 173–4,  
 182  
 military context, 202–6  
 military culture, 174  
 military dominance over civilians,  
 perceptions of, 200–201  
 military masculinity, 184–8  
 miscarriages, 66, 159, 161, 162–3,  
 164, 171  
 non-combatant roles, 192–6  
 physical masculinity, 186–7  
 pleasure of war, 195  
 post-combat syndromes, 204–6  
 Post-Traumatic Stress Disorder  
 (PTSD), 205, 206  
 psychosomatic illness,  
 transmission of, 168  
 semen, 155–72, 181–2  
 semen, birth defects and, 166–7  
 soldier as embodiment of  
 masculinity, 173–4, 182  
 strength and masculinity, 175  
 support services, roles of, 192–6  
 technological domination, 190–91  
 testosterone, 154, 155  
 voluntary redundancies, 188  
 vulnerability, 191  
 weakness and masculinity, 174  
 women contaminated through  
 men, 162–3  
 women in war, 180–81  
 work and masculinity, 175–6
- Mattingly, C., 132  
 Mechanic, D., 139
- media  
 attention to GWS, 211–12  
 health scares, stories of, 210,  
 211–12  
 and information, 53  
 representation of war, 191  
 as vehicle for narrative, 133
- Medical Research Council (MRC),  
 50, 199  
 review of GWS, 19–20, 25n7, 164
- medicalisation of life, 217–18
- Melucci, A., 138, 152–3
- memory problems, 3, 45, 84, 165,  
 186, 232  
 traumatic memory, 12, 130
- menstrual difficulties, 159, 232
- meta-narrative, causes of GWS,  
 60–61
- metaphor, 9–11  
 birth defects as friendly fire, 168–9  
 friendly fire, metaphor of, 113–14,  
 118–20  
 military metaphors for immune  
 system, 115–20
- military  
 context of masculinity lost, 202–6  
 culture, 174  
 dominance over civilians,  
 perceptions of, 200–201  
 masculinity and, 173–4, 182, 184–8  
 metaphors for immune system,  
 115–20  
 militarism and masculinity, 189–90  
 soldier as embodiment of  
 masculinity, 173–4, 182
- Miller, Danny, 174n11  
 Miller, I.C. et al., 139

- miscarriages, 66, 159, 161, 162–3, 164, 171
- misinformation, credibility and, 50, 54–5
- MMR (Measles, Mumps and Rubella) vaccine, 2, 25, 39, 111–12, 209, 212  
scare caused by, 212
- modernity, risk culture in, 39
- mood swings, 21, 27, 66, 85, 120, 155, 169, 178, 231
- morality  
moral evaluation of GWS, 47  
risk and, 40
- Morgan, D., 184, 186, 189
- Mosse, G., 185, 187, 191
- Motor-Neuron Disease (MND), 19, 179
- Muhammad, John Allen, 201n9, 202
- Multiple Chemical Sensitivity (MCS), 4, 88
- Multiple Sclerosis (MS), 58, 103–4, 138, 178–9
- MUPS ('multiple unexplained physical symptoms'), 85, 144
- Murphy, R.F., 197
- MUS ('medically unexplained syndromes'), 3, 4, 214, 215, 217, 219
- muscular fitness, 173, 177, 186, 187
- muscular problems, 79, 86, 231
- Myalgic Encephalopathy (ME), 72, 85, 121, 163, 214  
*see also* Chronic Fatigue Syndrome (CFS)
- myasthenia gravis, 36
- Nader, L., 51, 52, 53
- NAIADs (chemical weapons detectors), 31
- Napier, A.D., 68, 113, 115
- narratives  
collective narrative, 130–31  
GWVA and construction of, 126–39  
institutional structures and GWVA 131–2  
linking of health problems, 125–6  
media as vehicle for narrative, 133  
of misfortune and failure, 130  
narrative fit, 132  
personal experiences and, 127–33  
of self-help, 131  
uncertainty in, 127–9  
war as filter for negativity in, 132  
word of mouth, narrative spread and, 132–3
- National Geographic*, 115
- NBC (Nuclear, Biological, Chemical) attack, 35, 82, 92, 97
- nebulosness, 57–8
- Neisser, U., 130
- Nelkin, D. and Tancredi, L., 129
- Nerve Agent Pre-treatment Sets (NAPS), 1, 22, 27–8, 36–7  
body substances and, 70, 73, 81, 83–4  
impotence and, 157–8  
women, effects on, 180–81
- Nettleton, S., 52, 215
- neurasthenia, 220–21
- New York Times*, 32
- Newsnight* (BBC), 1
- Nicholson, Garth, 159, 159n1, 162
- Nicholson, Nancy, 162
- Nichter, M., 4, 130, 222
- night sweats, 232
- nightmares, 128, 147, 231
- non-combattant roles, 192–6
- non-exposure factors, 35
- Norman, M., 93
- Obeyesekere, G., 219
- The Observer*, 156
- opoid peptides, 85
- Options for Change, 86, 133, 188, 192, 196, 199, 207, 210
- organophosphates, 1, 17, 28–31
- Overing, J., 52, 57
- overload of immune system, 110–12
- Paine, R., 51, 54
- palpitations, 66, 181, 205, 231
- paranoia, 75, 231
- patient activism, 152–3

- Payne, K. and Gray, C., 190
- Peakman, M. et al., 25n7
- Pennebaker, J.W., 139
- permeability  
 of bodily boundaries, 97  
 permeability theory of body  
 substances, 84–5
- Perot, Ross, 30, 145, 176
- Petrie, K.J. et al., 120
- Philosophical Transactions of the Royal Society*, 20
- physical masculinity, 186–7
- pins and needles, 27, 66, 231
- Polanyi, Michael, 59
- polarisation of debate, 3, 143–52
- Polotrak, M. et al., 112
- post-combat illness, 3
- post-combat syndromes, 204–6
- Post-Traumatic Stress Disorder (PTSD), 12, 21, 27, 33, 58, 145–50, 205, 206
- post-war identity and community, creation of, 133–7
- power and risk, 41
- psychology  
 denial of psychological explanations, 141–52  
 immune system as psychological arbitrator, 107, 121  
 stigmatisation of psychological distress, 151–2
- psychosomatic illness, transmission of, 168
- pyridostigmine bromide (PB), 27, 83–4, 157
- Rabinow, P., 152
- Racy, J., 219
- Randall, G. and Brown, S., 202
- Randolph Higonnet, M. et al., 203
- rashes, 68, 88, 127, 130, 138, 155, 158, 160, 231
- rationality, 8–9
- reality of GWS, question of, 12–13
- Repetitive Strain Injury (RSI), 225
- respiratory problems, 232
- risk  
 anxiety and, 2  
 chance, risk averseness and, 40–41  
 corporatism and risk, 41–2  
 decision-making on, social nature of, 39–40  
 emphasis on, 44  
 of GWS, 39–42  
 health and, 213–14  
 individualisation and, 39–40  
 internal risks, 87–90  
 modernity, risk culture, 39  
 morality and, 40  
 power and, 41  
 vulnerability and, 212–16
- Rook, A.W. and Stanford, J.L., 107
- Rook, G., 107
- Rook, G. and Zumla, A., 48, 108
- Rose, M., 190
- Rose, N., 137
- Rumsfeld, Donald, 82n8
- Russell, Bertrand, 221
- Sahlins, M., 8
- Salzman, A., 220
- Saris, A.J., 131
- saturation of immune system, 111
- Scheper-Hughes, N. and Lock, M., 5, 10, 11, 207, 219, 222, 229
- Schindler, L., 117
- Schmitt, E., 191
- Schott, Paul, 21
- science  
 picking and choosing from scientific information, 212–13  
 scientific view of GWS, 18  
 specialisations of, 49, 52  
 western science, challenge to, 51–2  
*see also* biomedical
- Scott, P. et al., 226
- Scott, W., 206
- self-esteem, 174, 185, 186, 231
- self-help, narratives of, 131
- self-production of biography, 137–9
- self *versus* non-self, 112–15, 121
- semen, 1, 67, 83, 92, 175, 177, 183–4

- birth defects and, 166–7  
 masculinity lost, narratives of,  
 155–72, 181–2  
 Serrano, R., 202  
 Shand, A., 182  
 Shephard, B., 195, 203, 203n10  
 Shorter, E., 94, 121, 131, 137,  
 163n2, 212–13, 214, 216  
 Showalter, E., 53, 67, 132, 203, 215  
 Shriver, T., 131–2, 206  
 Shriver, T. et al., 132, 139, 153, 184,  
 187, 201  
 sick building syndrome, 214  
 sickness, 40, 55, 153, 184, 187, 210,  
 229, 232  
*Silent Spring* (Carson, R.L.), 170  
 Silverman, D., 138  
 Silverman, K., 184, 203, 204  
 sinus problems, 231  
 Skaine, R., 190  
 skin, 67–8  
 Skultans, V., 126  
 sleep problems, 19, 74, 107, 175,  
 181, 231  
 Slovic, P., 47  
 Soames, Nicholas, 55  
 somatism, 143  
   anthropology and, 218–22  
   chronic somatisation, 220  
   conversion symptoms, 220  
   GWS as ‘functional somatic  
   syndrome’, 215  
   interpretation of somatic  
   symptoms, 222–3  
   somatic symptoms and GWS, 4  
 Sontag, S., 9, 10  
 Sperber, D., 9  
 spinal disk disease, 231  
 spit, 67, 77, 91  
 Stansbury, J.P. et al., 198, 201–2  
 Steele, Lea, 114n14  
 Steincamp, J., 110  
 Stewart, D., 217  
 Stewart, K., 59–60, 61  
 Stimpson, N.J. et al., 147  
 Stockl, Andrea, 113n12  
 stomach problems, 3, 21–2, 27, 86,  
 107, 127, 141, 161, 227–8, 232  
 Strange, P., 185  
 strength and masculinity, 175  
 stress, 19, 48, 84, 121, 144, 157, 174,  
 176, 198, 231  
   as causal factor in GWS, 141–2,  
   185, 224  
   extreme stress, 26  
   immune system and, 107  
   psychological distress and, 148  
   psychoneuroimmunology, 107  
   PTS (post-traumatic stress), 146,  
   149, 151  
   of war, 29, 38, 145  
   *see also* Post-Traumatic Stress  
   Disorder (PTSD)  
 Stromberg, P., 129  
 substance abuse, 232  
 sunlight, sensitivity to, 66, 231  
 support services, roles of, 192–6  
 sweat, 67, 73, 77, 86, 89, 92, 128,  
 185  
 symptoms  
   language of, 5  
   patterns of, 19–20  
   reporting of, attention to, 229  
 Tambiah, S., 52  
 Tauber, A., 121  
 technological domination, 190–91  
 temper problems, 86, 178, 232  
 tendon pain, 231  
 testosterone, 154, 155  
 theories of causation  
   accommodating nature of, 58–9  
   constant change in, 6–7  
 Theweliet, K., 203  
 thrush, 66, 232  
*Time*, 115  
 time, feeling of loss of, 232  
 tiredness, 1, 107, 159, 175, 231  
*Today*, 93  
 tolerance thresholds, decline in, 214  
 total allergy syndrome, 214  
 toxicity, 11, 71, 73, 76–7, 149, 160,  
 229  
   of body substances, 67

- contagion and, 209  
of semen, 177, 181, 183  
somatic symptoms and, 222, 229  
toxic exposures, 20, 67, 69, 88, 148  
toxic oil fumes, 1, 71, 88  
of war, 142
- Trimble, M., 218
- truth and knowledge, claims to, 51–5
- Turner, B.S., 219
- ulcerative colitis, 105
- ulcers, 21, 76
- unnatural substances, 88
- Unwin, C. et al., 2, 19, 25, 108, 180, 204
- urination  
frequent urination, 28, 231  
problems with, 74
- urine, 73–4  
acryloylglycine (IAg) in, 72–3, 74, 85, 86
- vaccination, 1, 17, 27, 39  
immune system and, 108–10  
poisoning through, 21–5  
vaccine overload, 25–6
- vaginal infection, 163
- van der Straten, Ariane, 120
- van Dongen, E., 202
- van Dongen, E. and Reis, R., 202
- veterans' accounts of GWS, 20–23, 66–7, 125–6  
sense in, 18–19
- violence, 146, 155, 173, 182, 184, 193, 202, 203, 231
- viral illness, 232
- visibility of GWS, 79–80
- vision problems, 86
- voluntary redundancies, 188
- vulnerability, 191  
risk and, 212–16
- Walker, M., 97
- Wallman, S., 163
- war  
as anticlimax and letdown, 195  
as filter for negativity in narratives, 132  
glamour of war, 195  
killing and war, 195–6  
media representation of, 191  
pleasure of war, 195  
toxicity of, 142  
women in, 180–81
- Ware, N., 220
- weakness  
in immune system, 96  
and masculinity, 174
- Weber, Max, 41
- weight problems, 67, 73, 81, 137, 138, 155, 173, 232
- Weller, M.P., 220
- Wessely, S. and Freedman, L., 19–20, 120
- Wessely, S. et al., 131, 133, 142, 150, 151, 152, 214, 215
- Wessely, Simon, 94, 119n16, 138, 143, 143n7, 150
- Wheelwright, J., 27, 30, 32, 75, 83–4, 170–71, 215
- White, I., 211
- Wikan, U., 211n1
- Wilce, J., 221
- Wilce, J. and Price, L., 115, 221, 221n1
- Williams, G., 126
- Winch, P., 56–7
- Witchcraft, oracles and magic among the Azande* (Evans-Pritchard, E.), 11, 18, 55, 56–7, 59, 214
- women  
contaminated through men, 162–3  
different men, women's  
identification of veterans as, 140–41  
diseases of “old women”, 177–80  
effects of NAPS on, 180–81  
female sufferers of GWS, 180–81  
role of, 139–41
- word of mouth, narrative spread and, 132–3
- work and masculinity, 175–6

World Trade Centre Syndrome,  
211–12

Wynne, B., 47, 54–5, 57

*The X Factor*, 97

Young, A., 12, 130, 147, 206