

## Conclusion

# **GWS AND WORLD TRADE CENTRE SYNDROME**

---

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.