Chapter 2

Chains of Causation, Chains of Knowledge

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, govermnent) "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.[1]

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"[2] (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.[3]

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 Feyerbend (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 dominatory, 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 Gnau 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,[4] 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.