

What Do We Talk About When We Talk About Disease?

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I, Harry Quinn Schone, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

This is a thesis about classification and disease, our expectations as lay-people and patients as to where the borders of illness lie, and the consequences of such expectations. In Chapter I the discussion is framed with a critical analysis of common terms and concepts employed in the social, historical and philosophical study of disease. Chapter II revolves around a critique of sections of the philosophy of medicine literature, based upon the notion that any attempt at a 'universal' definition of disease is likely to fail. Chapter III introduces and appraises the work of three thinkers - Edward Shorter, Elaine Showalter and Ian Hacking - in order to give more historical weight to the case study which follows.

In Chapter IV, the final chapter, the main body of evidence is presented. The condition under examination is fibromyalgia and the bones of the chapter come from twenty-two semi-structured interviews with patients about their experiences. It is argued that disease definition is not a procedure conducted in the abstract but rather a fleshy, intuitive process that all of us, specialist or not, partake in. It is demonstrated that certain expectations of disease exists among the population - what it should look like, what it should act like - and that these expectations have a greater role in constructing a patient's identity than is often assumed. It is suggested that a patient might find themselves in harmony with their institutional category, have a pleasant and working relationship with their doctor, but still exist in total discord with those around them on the basis of their condition, a state of affairs not adequately considered or explained by the current philosophy of medicine literature.

Contents

Acknowledgements	5
Introduction	9
Chapter I - Key Concepts	15
Chapter II - Definitions of Disease	82
Chapter III - Shorter, Showalter, Hacking	135
Chapter IV - Fibromyalgia in Context	197
Appendix I - Methodology	309
Appendix II - Study ethics sheet	315
Bibliography	316

Acknowledgements

Some thanks are in order. First and foremost, thank you to all of the patients who responded to my request for help with this project. I would not have been able to complete this work without your words and insights. I wish you all well.

Thank you Brendan for our walks through Bloomsbury, for your tangent-taking and intuition, your careful, constructive notes and most of all for having faith in me and my methods when others may not have done. I always looked forward to our meetings and I will miss them. Thank you Jack for your attention to detail and compassionate disparagement. I needed that. Thank you Maël for kindly taking the time to read through draft chapters and offer thoughts. Thank you to the ESRC for (mostly) leaving me alone. And thank you Chiara for saving my skin all those years ago.

Thank you Phil for always lending money and never asking why. Thank you Agne for surrendering your laptop so generously. Thank you Brighton, London, Budapest and Reykjavik for being my home during these salad days.

Thank you Grandma, renowned master of Scrabble and corrector of library books.

Thank you Ieva for making me laugh every single day. You remind me that there is more to life than books.

Finally, thank you to my parents. I owe it all to you, for better or worse.

This work was supported by the Economic and Social Research Council.

'Pain, as a symptom of the problematic, frequently is'.

Drew Leder

For Chris

Introduction

This is a piece of work which aims to look in detail at the philosophical context that frames the ways contested, chronic illnesses are experienced and understood by patients in the early 21st century. Nestled inside this subject sit many concepts which require further discussion and critique, and I shall go through them in turn. The key focus of this research is to trace with greater accuracy and, more importantly, greater reference to lived experience, the contours of belief and assumption which provide us with our collective map of disease.

There is not an easy category in which to place this work. It is part historical, in that I utilise the writings of historians to provide insight into our contemporary concerns. It is impossible, I suppose, to understand the current state of disease beliefs prevalent across society without paying attention to the historical processes which have deposited a way of viewing and feeling disease into our collective subconscious. This work is also in part sociological, in that I borrow from sociology ways of listening and observing illness.¹ Furthermore, sociology has given us the most substantial attempt to reject or at least reform the biomedical view of the body by highlighting the cases in which it is inappropriate and ill-fitted, and to this research I shall refer at several points. And though this work is clearly interdisciplinary, it is perhaps most of all philosophical. Throughout my discussions I return time and time again to fundamental questions of conceptualisation: what do we expect a disease to look like?- what prevailing notions dictate the way we are allowed to, expect ourselves to be, and in some way *are* ill?- to whom does epistemic authority over these ideas belong to and originate from?

I mean these questions to be read in a philosophical sense as attempts to probe beneath the surface of our *reaction* to disease. In other words, how does a sick person

¹ The semi-structured interviews I conducted were guided in part by previous sociological approaches to medical narratives.

understand their illness metaphysically, how do people around them approach it and what are the consequences of these beliefs?

My argument, to be expounded greatly in the following pages, can be summarised as follows. Many, if not all, of the different concepts that philosophers associate with illness suffer a great loss of clarity under stringent investigation, and it is doubtful whether they are theoretically resilient enough to be relied on when constructing a coherent theory of disease. What does emerge from their examination, however, is a more general impression, a broad framework through which it is possible to view the way disease is mediated and understood. From this we are able to envisage what shape illness takes on unconsciously, implicitly, in the imagination, the ways in which it is expected to show itself and the ways in which people and institutions are expected to relate to it. In short, the way disease *operates* in our society.

With this idea in mind, I then introduce ‘chronic, contested illnesses’, those which do not conform to our vision, those which lie outside of our expectations. These have a long and troubled history, intermingled most often with psychiatry. They present themselves in many forms, and a fuller description will be given below. The aim is not to show that people with these conditions ‘really are’ ill, or are deserving of sympathy, though this is in my view certainly true. Rather, I want to put it that we intuitively categorise disease according to certain predispositions, and when we encounter a phenomenon which contradicts these prejudices, a gap opens up between our expectations of disease and the condition itself, the thing before us. This gap creates a tension, a painful distance, but it is not purely theoretical. On the contrary, it is precisely in this space that harm occurs. This is found institutionally, in the form of welfare disputes or dismissals from employment; interpersonally in the breakdown of trust and respect in a marriage; psychologically in the self-doubt and depression of an ill person who lacks an approved way of deciphering the way they feel in their body.

My thesis is that whilst much attention has been given to both analysing concepts related to disease and to investigating the relationship between institutions and individuals of authority and patients, little focus has been granted philosophically to the ways in which we all - as friends, family members, colleagues, patients - contribute to and constitute the experience and meaning of disease. In other words, I think that the quest to define disease, to map the landscape of the doctor/patient relationship, to understand how patients interact with their condition as described to them institutionally has eschewed broader questions about the underlying metaphysical assumptions that exist in the minds of clinicians and non-specialists alike. Essentially, I say that we cannot define disease, but we can look at the ways it *is* defined, who is doing the defining, on what basis they make that distinction, and what the effects of such a demarcation are.²

The structure of this work should hopefully impart a sense of cumulation. In the first chapter I will discuss the various ways in which disease, illness and sickness have been employed conceptually, and account for my partial rejection of such distinctions. Other concepts which orbit this topic will also be explored: biomedicine, malingering, issues of legitimacy, validation and the role of the patient community. The aim of this discussion is to establish a conceptual context for talking about disease, to compile a language that engages with and enhances my case-study. I will then look at terms such as chronic and contested illness, recognising the slippery edges of such things but arguing that our understanding of them is adequate enough to justify using them as categories.

My second chapter will consider how philosophy of medicine has responded to the problem of disease, specifically its definition. Though nearly half a century of largely analytic literature exists on the topic, very little is of applicable utility to the

² These sound like very sociological questions. But what I am trying to get close to is outlining the unconscious, seemingly intuitive set of beliefs and expectations that cause a person to look at another and say 'you are sick' or 'you are not ill', a process that I think too obscure and too internal to be classified as an object of sociological inquiry.

problems of chronic, contested illnesses. I consider a case crying out for definition, Morgellons, and use this example to demonstrate the penury of the disease definition literature in terms of problem selection and applicability.³ I then offer a short historical analysis of the definition of disease literature which provides an original and critical thesis as to the discipline's shortcomings, contending that the search for an all-encompassing definition of disease is futile. I provide two main arguments for this perspective: my vast magnitude argument and my justification gap argument. The first of these posits that there are simply too many entities that *might* qualify as disease to be accurately captured by a singular definition without entailing the conceptual entrapment of those things which we would not consider disease. The second makes the point that philosophers of medicine provide little in the way of justification as to why their stipulations should be taken up by medical decision makers.

This is not the only philosophy that has relevance, however, and my third chapter will review work from other perspectives which come to bear on this topic. I will examine Ian Hacking's ideas about the looping effect of human kinds, alongside Edward Shorter and Elaine Showalter's work about psychosomatic illnesses. The outlooks they provide give a historical view, and ask interesting questions as to the extent that contested illnesses are constructed (that is, produced and sustained by social trends), raise issues of intertextuality and provide insight into the complicated reasons why these conditions struggle for legitimacy.

The fourth chapter of this work deals with my main case study, fibromyalgia. I conducted semi-structured interviews with patients from the UK and the US, try-

³ Morgellons is a disease state which is heavily contested by doctors and patients who subscribe to wholly different aetiological models. Patients (and a small group of research-activists) believe that they have an organic dysfunction which causes painful filaments or fibres to grow from their skin, creating lesions that do not heal. Doctors believe that patients have delusions of parasitosis, a long recognised psychological condition where individuals believe that something is crawling or growing beneath their skin, which they then lacerate in search of relief.

ing to tease from their experiences a feeling of the philosophical assumptions which underpin the troubles they face. It is here that I utilise the concepts discussed in Chapter I, mapping them on to real life struggles, told in the words of those who experience them, and here which I hope to expose the myopia of the philosophical work referenced in Chapter II. The works discussed in Chapter III are also analysed, in that it becomes clear that individuals with these conditions are far more self-aware and reflexive than is sometimes assumed. This may not in fact be a negative reflection on those theorists' work, but rather a demonstration of increased individualism in a new era of truly mass communication and fluid identities. The ambition in this chapter is not to construct a new philosophy of disease, or to say that one can be, but to lay as bare as possible the ways in which *our* philosophy – the beliefs of doctors, patients and the people around them – is unable to incorporate all of our distress.

In this final chapter I will conclude with a reassertion of the importance of disease as a topic of philosophical enquiry. It is one which can tell us much about our relationship with our bodies and the environment. What is more, it offers us an appreciation of the profoundly moral way in which we discuss supposedly natural processes, the importance to each individual of being validated by a larger belief system and the consequences of a medical superstructure based on reduction and detection for entities which can neither be reduced or detected. Though it is hard to remain optimistic, given some of the circumstances of patients, it is also emphasised that only through further conversation, closer analysis and greater empathy can this topic be better understood.

Caveats, of course, abound. This is not a medical thesis, and does not aim to answer any questions of medical science. What this work tries to achieve instead is an illumination of the way in which the medical aspects of a disease: diagnosis, labelling, treatment etc. intersect with social beliefs about sickness and contribute to the manifestation of illness in an individual, both in terms of their symptoms and

how they understand them, but also in terms of how those symptoms are greeted by others. Medicine is therefore just one of many components which have an effect on our idea of a disease, on our acceptance or rejection of a certain set of phenomena as a disease concept. It is afforded no special status in this analysis.

However, it should be highlighted that contested illnesses would benefit from more clarity in this (medical) and other areas, and I hope that my work on this topic might inspire others in different fields to approach these difficult questions. Doctors, psychiatrists, health researchers, sociologists and other philosophers will find some interesting topics discussed in this thesis and may wish to pursue them further within the scope of their own specialities.

Also to be noted is that the overriding emphasis of this work is not to generate universals or to speak in grand terms, but rather to examine the specific and draw from it certain insights which may tentatively be said to represent *something* if not nearly *everything* that can be said about the topic. As such, it is difficult to see how the conclusions of the work presented below could be extended confidently beyond a UK context. Though of course there will be similarities with the experience of people in other countries, the expectation that (in some cases subtle, in some cases vast) differences in outlook concretely exist prevents me from offering any detailed analysis beyond the borders of this country.

Furthermore, consistent with my stated commitment to specificity, this is a thesis that is ground in a precise time and place, and makes no claims to represent anything more than a snapshot of that particular moment. I take a lead from Floridi, who writes that any ‘timeless’ philosophy is a stagnant one.⁴ This is a piece about disease as it is lived and understood here and now and nowhere else.

⁴ Floridi, L. *The Philosophy of Information*, 2011, Oxford University Press, UK, p.12.

Chapter I – Key Concepts

What do we talk about when we talk about disease? It is something both grand and personal, with a metaphoric and psychological power hard to adequately contain within a single definition. Parts of society can be *diseased*, an action can be *sick*, drinking culture can be a *cancer*, racism can be a *tumour*. And just as easily as we reach for these words do we proffer singular descriptions of ourselves and others as unwell, from the banalities of a cold to the life-threatening urgency of a cardiac arrest. To begin at the beginning, disease is clearly also something biological, or at least connected to biology, and intuitively we seek to retain this connection in our discussion. It is where disease would appear to start. Arguing that this is the case is not, I think, as interesting as asking the inverse question, namely: where does it end?- what does it encompass? Alongside disease we must surely place illness and sickness. Is it useful to distinguish between them? What gains are made by treating them as equivalent terms?

And then the central focus of this work: chronic, contested illnesses. Is a chronic illness simply a condition that has persisted for a certain amount of time, or is there a more inventive and instructive conceptualisation that can be reached? – what makes a disease contested? – are all diseases contested?

Examining these conditions present a host of related concepts: legitimacy, validation, responsibility, stigma. Are we able to make sense of these on their own or do they have to be viewed in relation to a larger understanding of disease? Then there exist certain outliers, such as malingering. Is it possible to tie down this idea in any useful way, or does it operate purely as a pejorative insinuation? Beneath it all, what is the ‘medical’ view, and how does it interact with the other concepts. Are we simply considering ‘biomedicine’ - whatever that may encompass - or is there a more convoluted and complex infrastructure at work here?

These may at first seem themselves to be slightly convoluted and complex questions themselves, but without attempting to answer them we leave ourselves bereft of an adequate language with which to talk about disease. In the following chapter I will attempt to develop or dismiss these ideas in a way which lays the groundwork for later discussion of real life examples, where I can hopefully begin to tie together the theoretical and the actual.

Disease, illness, sickness

Talcott Parsons famously wrote in 1951 about the rights and privileges that any ill person could expect to be afforded, providing they conformed with humble enthusiasm to certain anticipated behaviour, namely the ‘sick role’.⁵ Under his functionalist analysis, once one becomes ill it is possible to waive everyday obligations – work, school, being pleasant to others, dressing in a certain way – but only in exchange for a demonstrable change in attitude. Isolation is encouraged or in some cases demanded, doctor’s orders must be followed and above all a strong will to get better must be ostentatiously displayed. Infantile dependency may be allowed, but purely on the condition that it brings with it an equivalent childlike loss of independence.

This analysis has been debated for over sixty years, and despite many shortcomings it remains important to this work because of Parson’s original conception of sickness as a culturally understandable process, not something which acted upon an individual unknowingly.⁶ The crucial insight that is of relevance here is that illness can be so much more than simply feeling unwell; it can be an escape from the frus-

⁵ Parsons, T. *The Social System*, 1951, Routledge, UK; it might be worth noting that, though highly original, Parsons was writing in the tradition of Sigerist: see Sigerist, H. ‘The special position of the sick’ in Sigerist, H. *On the sociology of medicine*, 1960, MD Publications, USA.

⁶ *Ibid.*, 430.

trations of a complicated social world (Parsons describes this as ‘a tantalisingly attractive “solution”’), it can have moral implications and it cannot exist in isolation.⁷ Understanding sickness as something other than biological entity is of course not something startlingly original itself, considering the relatively contemporary nature of viewing disease biologically *at all*. Placing it within a wider scheme of roles and responsibilities, however, allows us to consider illness as something both personal and intimately connected to broader social infrastructure. Whether you agree that being ill is a form of deviance or not, it is difficult now to argue that we should think of sickness in terms which ignore society.

Defining exactly what ‘sickness’ means, however, has occupied medical sociology since Parsons. Literature in other fields such as medical anthropology and philosophy of medicine have reasserted by repetition the primacy of refining a distinct and useable definition. As a result, significant gaps have opened between the concept of sickness and its sisters disease and illness as they are understood and utilised.

To my mind the best, most lucid articulation of disease, sickness and illness as sociological concepts was written over 40 years ago by Marshall Marinka. His description to a remarkably full extent captured the way in which these ideas would be used in the years following. He starts with diseases: these are the ‘central facts’ that inform the medical view, they can be measured, quantified, somehow touched by apparatus and observation.⁸ There is an statistical objectivity to them, they present themselves as a ‘deviation from a biological norm’.⁹ Diseases, then, are discoverable, universal, comparable and consistent.

⁷ Parsons, T. and Fox, R. ‘Illness, therapy and the modern urban American family’ in Jaco, E. (ed.) *Patients Physicians and Illness*, 1952, The Free Press, New York, p.237.

⁸ Marinka, M. ‘Why make people patients’ in *The journal of Medical Ethics*, 1975, Vol. 1, p. 82.

⁹ Ibid.

Illness skirts such neat definition. It is ‘a feeling’, something inward, only accessible by the patient, an ‘underworld of experience’.¹⁰ Illness is a subjective, personal process and entry to it for outsiders is entirely reliant on the ways in which the individual chooses or is able to communicate their experience. Importantly, it is inconsistent and variable. Illness here is fully demarcated from disease, in that there is no obligation that one should follow the other, despite them so often being bed-fellows. To be ill but not diseased in the sense outlined here will occupy much space in this work. Not only is illness subjective, but it is also sometimes implied that unlike the other concepts it is something of a personal decision, as Boyd writes ‘whether or not someone is ill, is something the person concerned must ultimately decide for him- or her-self. But whether that person has a disease or is sick is something doctors and others dispute’.¹¹

Marinka adopts an essentially Parsonian view of sickness, in that being sick is regarded as a negotiation between a person and society over which liberties can be taken and how favourably or unfavourably their actions will be received.¹² It is a public manifestation, and does not require the presence of either disease or illness as antecedents. Boyd states that ‘the security of this role depends on a number of factors, not least the possession of that much treasured gift, the disease’.¹³ Still, a person could be regarded as sick by society and adopt the sick role without in fact having any discoverable, biomedical irregularities or indeed feeling unwell subjectively.

Consider the strange case of Joshua Norton, for example. A 19th century British-American businessman who lost his entire fortune due to an inopportune change

¹⁰ Ibid.

¹¹ Boyd, K. M. ‘Disease, Illness, sickness, health, healing and wholeness: exploring some elusive concepts’ in *The Journal of Medical Ethics: Medical Humanities*, 2000, Vol. 26, p. 11.

¹² Marinka, M. 1975, p. 83.

¹³ Boyd, K. M. 2000, p. 10.

in the rice markets, he emerged several years after this calamity to proclaim to the people of San Francisco that he was the ‘Emperor of the United States and Protector of Mexico’. Encouraged by the local press and a good-humoured public, he was permitted to dress in regal attire and indulged by greetings of mock reverence and ‘taxes’ wherever he went, despite continuing to live in poverty. Though retrospective diagnosis is a dangerous game, it is not such a stretch of the imagination to believe that had Norton been ‘suffering’ from that which is most likely - grandiose delusions, a psychiatric disorder with no identifiable organic base – he would have been sick but not ill or diseased.¹⁴

After Marinka, Arthur Kleinman added his voice to the discussion and strove for a more detailed though similar description of disease and illness, alongside an expanded vision of what sickness might mean. In his view, sickness incorporates all the macro-social elements of disorders, be it economic, class, gender, racial or institutional factors.¹⁵ Poor housing, job pressures, family life, all of these for Kleinman became elements of sickness that were previously ignored. His explicit desire in separating the three was to highlight the ways in which illness and sickness were ignored by a medical community overly focused on curing disease, and the lack of compassion, bad practice and poor public policy that resulted.

Since the work of these authors many subtle variations have emerged but most retain the basic distinction that disease is something biomedical, illness is something personal and sickness is something societal. An indicator of this continuity is Aho and Aho’s 2008 work *Body Matters: A Phenomenology of Sickness, Disease, and Illness*, where they write that disease is ‘an organic pathology as discerned by one or more recognised clinical or laboratory procedures’ and illness is ‘a non-quantifiable lived

¹⁴ For more about this fascinating character, see Lis, E. ‘His Majesty’s Psychosis: the Case of Emperor Joshua Norton’ in *Academic Psychiatry*, 2015, Vol. 39, No. 2, pp. 181-185.

¹⁵ Kleinman, A. *The Illness Narratives*, 1988, Basic Books, USA, pp. 6-7.

experience, not feeling well'.¹⁶ Later in the same text they sum up by stating 'physical and mental troubles show up in society as sickness-deviations to be corrected. To patients, they disclose themselves as illnesses. To doctors, ailments present themselves as diseases to be cured'.¹⁷ This view is virtually indistinguishable from that presented three and a half decades previously. Further evidence of the entrenchment of these conceptual boundaries can be found in other places. Wilkman *et al's* 2005 study, for example, attempted to operationalise disease, sickness and illness along these now-familiar lines. Professionally diagnosed conditions stood in for 'disease', self-reported bad health was used for 'illness' and 'sickness' was represented by absence from work on sick-leave.¹⁸

Although some theorists departed from Marinka and Kleinman's basic view, the essential features of their schema have remained unusually stable as sociological concepts. Such is the influence of their work that the idea of disease as 'objective', illness as 'subjective' and sickness is 'macro' or 'societal' is now in fairly common usage across not just sociology but also medical anthropology and the philosophy of medicine. Some disputes have occurred, but generally these have taken place within the predetermined boundaries described above rather than about the actual ontological validity of such distinctions.¹⁹

Given its longevity, this approach evidently has an enduring appeal to theorists. Indeed, it seems to fairly intuitively capture what are closely related and overlapping

¹⁶ Aho, J. A. and Aho, K. *Body Matters: A Phenomenology of Sickness, Disease, and Illness*, 2008, Lexington Books, USA, p. 3.

¹⁷ *Ibid.*, p. 77.

¹⁸ Wikman, A., Marklind, S. and Alexanderson, K. 'Illness, disease and sickness absence an empirical test of differences between concepts of ill health' in *The Journal of Epidemiological Community Health*, 2005, Vol. 59, pp. 450-454.

¹⁹ For example see Twaddle, A. and Nordenfelt, L. (eds.) *Disease, Illness and Sickness: Three Central Concepts in the Theory of Health*, 1993, Linköping University Press, Sweden; Hofmann, B 'On the triad disease, illness and sickness' in *The Journal of Medical Philosophy*, 2002, Vol. 27, No.6, pp. 651-673.

but distinct concepts. There is a sense of validity about the idea that a disease is an individual, measurable, pathological entity which *causes* you to feel ill, which then leads to a phone call with the boss and chicken noodle soup from your partner (i.e. the social benefits of sickness), but that these three concepts follow on from, interact with and are closely related to each other without being exactly the same thing. No doubt, too, for a theorist working to challenge a biomedical system that has obvious downsides for patients suffering from some conditions, the creation and assertion of these distinctions allows a shift in focus away from primarily reductionist medical concerns and a proclamation that the subjective and the societal matter. As such, Cecil Helman wrote in the 1980s that splitting disease and illness ‘has been one of the most useful contributions of medical anthropology’ and as recently as 2016 Havi Carel has asserted the desirability of separating them.²⁰

However, in this work, I intend to disregard these distinctions and talk of all three as if they refer to the same thing - a broader, more encompassing category in which all three terms do not relate to delineated processes but rather deal with the whole hog. To summarise my argument briefly, I would say that the problem with disease, illness and sickness lies primarily in the order in which they are found in this sentence. Though of course titles, approaches and motivations vary, what is almost invariable in the way that these concepts are employed in the literature is that *disease comes first*.²¹ It is the smallest, the most quantifiable, the easiest to define.

²⁰ Helman, C.G. ‘Disease and Pseudo-Disease: A Case History of Pseudo-Angina’ in Hann, R. A. and Gaines, A. D. (eds.) *Physicians of Western Medicine: Anthropological Approaches to Theory and Practice*, Springer, Netherlands, 1985, Vol. 6, p. 293; Carel, H. ‘Living in the present: Illness, phenomenology and well-being’ in Jackson, M. (ed.) *The Routledge History of Disease*, 2016, Routledge, UK, p. 587.

²¹ I mean this both literally in terms of word order and also in the sense that disease is implicitly epistemically privileged in the triad due to the reasons explained above. See, for example: Susser, M. ‘Disease, illness, sickness; impairment, disability and handicap’ in *Psychological Medicine*, 1990, Vol. 20, pp. 471-473; Boyd, K. M. 2000, pp. 9-17; Hofmann, B. ‘On the Triad Disease, Illness and Sickness’ in *The Journal of Medicine and Philosophy*, 2002, Vol. 27, No. 6, pp. 651-673.

And although examples of disease are virtually inexhaustible - the International Classification of Diseases 10 contains 141,000 codes - these pale into insignificance when considered alongside the near-infinite possible permutations of subjective experience present in illness and sickness. This lends the impression that vitally, disease is also the most *real* of the three concepts, given our collective metaphysical prejudices.²² The weight placed on ‘reality’ will become clearer when questions of legitimacy and validation are raised later in this chapter.

Illness comes after disease, and does not live in the objective world but rather the land of subject feeling, impressionistic, inward and unreliable. We are inclined to trust that something objective (measurable, reliably quantifiable) is better, more respectable, than the vagaries of personal experience. Sickness completes the trio by encompassing the wider aspects of morbidity that are difficult to ignore. Once again though this seems less concrete than disease, tied as it is to the whims of social values. I am writing in this manner not because I believe it to be a true representation of these concepts but rather because it is the impression that one gets from reading about disease, illness and sickness.

Medical sociology changed tack in the 1970s and 80s, abandoning its Parsonian roots for a model which was not so singularly suited to acute conditions and did not view illness as deviance.²³ Part of this new direction was placing emphasis on the split between disease, illness and sickness. Rightly, the separation of these ideas was pursued with the aim of provoking the realisation that clinical care in the last century also required patient and epidemiological perspectives in order to be truly humane and successful.

However, at this stage, the continued segregation of these terms serves in a subtle but persuasive way to reinforce implicitly the authority of medicine to decide what

²² See ‘Biomedicine’, this chapter.

²³ Pierret, J. ‘Constructing discourses about health and their social determinants’ in Radley, A. (ed.) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, 2002, Routledge, UK, p. 9.

is ‘disease’ and what is not. It is clear that although the three concepts are often said to be overlapping and interrelated, what they actually are is hierarchical. Disease sits atop illness and sickness in validity and importance. Granting this primacy to disease too easily and too neatly accedes epistemic authority to medical science. Some philosophers recognise this danger but, to my mind, avoid confronting it head on or with a prolonged rebuke. For example, Carel writes:

‘[The disease/illness dichotomy] does not imply that illness that is not accompanied by disease is less real or less significant than an illness that is. Indeed, our ability to identify disease is contingent and changes over time. Hence I am not suggesting that an illness that is not accompanied by disease is less real but merely that we have not (yet) identified the disease. The epistemic restriction, namely our current inability to identify the disease, should not drive any ontological assumptions about the reality or severity of the illness’.²⁴

It seems to me, however, that statements like this reveal a reverence towards disease as biomedically defined, seeing as the validity of illness hinges here on an hypothetical and underdetermined future in which all illnesses are explicated by disease processes discovered according to biomedical parameters. When reading passages such as this one it also strikes me that though our current inability to align disease and illness *should not* indeed ‘drive any ontological assumptions about the reality or severity of the illness’, our good intentions do not prevent it from doing so in actuality, whether in the clinic or the street. The question then becomes, I think, whether or not this approach of splitting disease and illness helps or hinders the problems which arise from having illness but not disease. I do not believe that it has

²⁴ Carel, H. in Jackson, M. (ed.) 2016, p. 587; Carel perhaps has one further reason to favour this distinction: it maps neatly onto the phenomenological concepts of the objective body and the body-as-lived, canonical conceptualisations within her discipline.

a positive effect in this regard, largely because this dichotomy cements the epistemic authority of medical science in constituting the meaning of disease and relegates illness to a subsidiary role, perhaps bolstered by the presence of disease but never granted the same authority.

This arrangement of concepts also seems to ignore wider trends in philosophy and sociology of science, which have from the late 20th century sought the challenge the unquestioned acceptance of science's epistemic authority.²⁵ I do not want to go down this route and rehash what are by now well-worn disputes, but I think it is important to highlight the incongruity here. As sociologists, philosophers, anthropologists or whatever, we challenge and have challenged science everywhere and yet in this instance we continue to work within the disease/illness/sickness dichotomy. This implicitly removes our analytic hands from 'disease', assuming that it is the preserve of medical science.

The danger here is that the use of such conceptual cleavers has an effect on the way we treat the resulting categories: in order to highlight and criticise the deficiencies of reductionist medicine, we have created separate groupings which allow medical science a designated space in which to be reductionist without analytic confrontation. This, and to be clear I am talking about present discussions (I fully acknowledge the previous usefulness of such distinctions), is counterproductive. Not only does it suggest that all disease definition is an impartial, medical process - something not borne out by empirical evidence of politicisation, borderline cases, pharmaceutical influence etc. - it also seems to accede all of the fundamental *mean-*

²⁵ I am thinking not only of the Strong Programme and the work of Latour (who, despite their differences, both believe the scientific production of knowledge is ripe for critical analysis), but also of more recent work such as Douglas, H. E. *Science, Policy, and the Value-Free Ideal*, 2009, University of Pittsburgh Press, USA.

ing of disease to abstract, impartial, scientific forces.²⁶ As will become evident throughout this thesis if it is not already, disease is messy. Advancing in our analysis as if it is possible to isolate that which is medically determined and, furthermore, placing that atop the conceptual heap in terms of validity, seems to me a foolish way to move proceed.²⁷

But perhaps I am coming at this from the wrong direction. We should consider for a moment the idea that it may not be disease which is easily bracketed from the other two (and therefore should be separate) but illness. By virtue of its inwardness, its subjectivity, we might say that some important part of illness is incommunicable. It is in other words fundamentally personal in a way that disease and sickness are not. A disease, at least abstractly, exists with some consistency across populations of people, whereas illness as constructed here can only be accurately discussed in terms of individuals. Illness is different in each person it occurs in, whereas plenty of people can be said to have the same disease.

There are a number of ways you could respond to this. Firstly, you could simply accept this argument and use it as a further buttress for the necessary separation of the concepts. Or, you could say that, actually, illness does have universal, consistent features and is comparable to disease in that sense (this is a line of thinking taken up by Toombs and discussed briefly below, p. 90). These essential features, however, suffer from not being *as* essential as those found in disease processes, and from

²⁶ That is to say that under this schema, any meaning not associated with the disease as constructed by medical science is placed in some other category - 'illness', 'sickness', 'patient experience' etc. and regarded as something related but separate. The fundamentals of disease thus become decided on an entirely scientific basis.

²⁷ There are of course permutations in the viewpoint I have outlined. You could, descriptively, argue that disease is that which is captured by medicine without being compelled to accept the validity of that discernment, as Aho and Aho do: Aho, J. A. and Aho, K. 2008, p. 3.

being constituted in what I would consider a significantly different manner.²⁸

My response would be to say that there is nothing about the supposed incommunicability or isolated nature of illness that generates an unbridgeable gap between it and similar or related concepts. For me it simply sits at the same juncture- the crunch point where biological disharmony, social responses and individually experienced symptoms collide. Subjective reaction does not need to be bracketed as it is a sufficient if not necessary component of disease, or illness, or sickness.

Once you remove the barrier between disease, illness and sickness, have you simply adjusted the power balance in the doctor patient relationship? Is this the same thing as saying that anyone has the right to produce explanations of disease, regardless of their qualifications? The answer to these questions is that simply removing the conceptual distinction between disease, illness and sickness will not directly influence epistemic power relations. Medical science and its institutions remain the most influential arbiter of meaning related to illness that exists in society, but that does not mean that we should allow it special analytic privileges. By treating disease, illness and sickness as one, larger phenomenon, we achieve several things.

Firstly, the inbuilt, implicit hierarchy that assumes 'disease' is the most important aspect of a condition is reconfigured, and we are encouraged to consider other factors, or at least to contemplate the way the puzzle pieces fit together. This reflects the fairly widespread constructivist critique of objectivity in scientific knowledge, and reminds us that scientism should not go unchallenged or unquestioned. Organised biomedicine is not somehow ineffective or *bad*, it is just that giving it such an elevated role can be counter productive. As Mansbridge writes:

²⁸ That is to say, the inconsistencies in illness experience are far greater than those in disease detection and it is arguable that something like the loss of freedom (i.e. illness) is fundamentally different from the presence of helicobacter pylori in your stomach (i.e. disease).

‘Inequalities in power have their most insidious effect when the dominant group has so much control over the idea available to other members of the society that the conceptual categories required to challenge the status quo hardly exist. Ideological hegemony of this sort pervades every human society in ways that are, by definition, hard to bring to conscious awareness’.²⁹

Or Kitwood:

‘The discourse generated by medical science is so dominant, and supported by such power and prestige, that its anomalies, self-contradictions and nonsequiturs are obscured from view’.³⁰

And this is precisely what happens when we fully accede to medicine the concept of disease: we rob ourselves of the tools to shine a light on these obscurities and properly resist outcomes which may seem misguided, warped or harmful. In this way I feel that combining the terms in fact carries on the previous work done in sociology to encourage a broader understanding of illness and confront the apparent omnipotence of medicine to decide upon disease.

Furthermore, setting down disease, illness and sickness together rather than apart represents a more sensible use of language. Connotations do oscillate with context, and there are differences between the words, but there is really no substantive dis-

²⁹ Mansbridge, J. J. ‘The making of oppositional consciousness’ in Mansbridge, J. J. and Morris, A. *Oppositional Consciousness: The Subjective Roots of Social Protest*, University of Chicago Press, 2001, USA, p. 4.

³⁰ Kitwood, T. ‘Towards the reconstruction of an organic mental disorder’ in Radley, A. (ed.) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, 2002, Routledge, UK, p. 142.

tance between *the ill*, *the sick*, and *the diseased*. To label someone sick but not ill has little relevance beyond the philosophy and sociology of medicine, and does not represent how people relate to these concepts in their everyday lives. Many other languages do not draw any distinction between them. French generally uses some variation on *malade*. The German *krankheit* leans more towards disease whilst *erkrankung* is closer to illness, but largely they are used synonymously. Lithuanian, as a further example, does not distinguish between the three (*liga* is used for all).

Clouser, Culver and Gert examined the different ways that disease and illness were used (alongside other terms like injury) and in response proposed that ‘malady’ be used in all cases to describe ‘roughly, any condition in which there is something wrong with a person’.³¹ Their argument was that though there are ways to distinguish between disease, illness, disorder, wound, trauma etc., these concepts suffer from an ‘arbitrary element’ in their labelling, and as such should be abandoned in favour of an umbrella description.³² The strength of their analysis lies not in their conclusion, and indeed their proposed new descriptive category seemed to create new problems and did not garner support, but rather in the way they highlight the ambiguous and idiosyncratic use of terms across clinical practice and by different groups.³³ For Clouser, Culver and Gert, disease, illness and sickness had been defined too clumsily, in a manner which morphed and overlapped at great variance depending on who was doing the defining and for what purpose. This is close to my position.

Replacing disease, illness and sickness with disease, illness and sickness enables us

³¹ Clouser, K. D., Culver, C. M. and Gert, B. ‘Malady: A New Treatment of Disease’ in *Hastings Center Report*, 1981, Vol. 11, Is. 3, p. 29.

³² *Ibid.*, p. 29.

³³ Their definition of ‘malady’ was as follows: ‘a person has a malady if and only if he or she has a condition, other than a rational belief or desire, such that he or she is suffering, or at increased risk of suffering, an evil (death, pain, loss of freedom or opportunity, or loss of pleasure) in the absence of a distinct sustaining cause’. *Ibid.*, p. 36

to examine the various features of a condition as if they belong to the same thing, rather than individual parts whose relationship is unclear. Thus we can speak of a condition, largely regarded by doctors to be X (with associated clinical features, prognosis etc.), which can manifest in a patient as Y, whose causation or exacerbation can be traced to environmental stress factors, which is generally treated through Z and consider the whole picture to be *the disease*. The focus here then becomes precisely how these different factors interact to produce a certain experience of illness, which parts exert the most power (ontologically, epistemically, psychologically) and whether or not this is a benevolent and positive system. As Annemarie Mol states:

‘The disease/illness distinction is no longer helpful. When doctor and patient act together in the consultation room, they jointly give shape to the reality of the patients’ hurting legs. How to call what they thus shape? If I use the word *disease* here, this is not to locate my text on the disease side of the disease/illness distinction, but to breach it’. (Emphasis in the original).³⁴

In other words, no illness is purely a microscopic abstraction, and nor is it entirely an emotional or symptomatic response, but rather a complex set of circumstances, and employing holistic language to describe and explain this more accurately represents its multifaceted reality. The pathogen is part of the disease and the illness and the sickness, as is the pain in a person’s gut, the living conditions that allow it to spread and the way that the reporter talks about it on the news. We do ourselves no favours by separating and differentiating the three concepts and approaching them individually as if they can only be analysed on their own.

³⁴ Mol, A. *The Body Multiple*, 2003, Duke University Press, USA, p. 27.

Chronic, contested illnesses

To better be able to examine disease, it is good to focus on one aspect of the concept. Honing in on a specific area is important for detail and accuracy but also at some point for explanation. Making grand statements about disease as a whole assumes that such statements can be made at all, and it is better to shine a light on a small corner and speculate from that than stare into space and try to describe it all.

That is not to say that I have decided to address an area of this topic at random.

On the contrary, by choosing to look at chronic, contested illnesses I have quite deliberately picked a group of diseases that live within the crux of many philosophical problems. These are the conditions unaccounted for by biomedical models, the ailments that debilitate and destroy without explanation or acceptance. They often straddle physical and mental, but share a sense of dislocation; doctors are not trained to help their non-specific pain, partners are not naturally inclined to sympathise and institutions are not willing to accept them as genuine. They are precisely those illnesses which disconnect from our expectations of disease, and in the gap created lay bare our previous assumptions about what a disease is or what is necessary for someone to be sick. But is this a useful category, or indeed a category at all? Is it possible to adequately define a chronic disease, or a contested illness?

Let us start with the former.

Chronic diseases attract attention from all sorts of groups in part because they present huge costs to healthcare systems around the planet, though most notably in the developed world.³⁵ Essentially, the better doctors become at treating short-term, self-limiting conditions, the more the burden of healthcare transfers to

³⁵ This is not to say that parts of the developing world will not find themselves in a similar situation as their acute medical care improves and life expectancies rise, see Choi, B. C. *et al* 'Enhancing global capacity in the surveillance, prevention, and control of chronic diseases: seven themes to consider and build upon' in *Journal of Epidemiology and Community Health*, 2008, Vol. 62, No. 5, pp. 391-397.

longer-lasting, less curable diseases and the medical emphasis switches from response to management. Already, chronic conditions are estimated to account for up to 70% of deaths in the USA and it has been noted that demographic trends, especially in the UK and US, point towards an unbalanced population with disproportionately more older people than ever before.³⁶ Thrall notes that ‘the magnitude of the population burden of chronic disease is eye-opening’.³⁷

However, despite these concerns and the worrying prognosis above, an established definition of ‘chronic disease’ - whether clinical, policy-focused, philosophical or sociological - is a hard to find. Many researchers note that it is not a static concept, displaying ‘genuine ambiguity’ or that different models and conceptualisations are used to suit the context.³⁸ Even then, explicit definitions are rare, and there is little agreement across disciplines as to what constitutes a chronic disease or which diseases could be classified as such. This lack of specificity, or failure to operationalise chronic illnesses, may be a function of the medical apparatus we expect to be able to analyse them with. As Martin writes, chronic diseases do not fit readily ‘into a biomedical or administrative classification’.³⁹

It is clear, however, that some essential features of chronic conditions can be discerned, and indeed there are certain intuitive elements which reoccur across most conditions. As much of a banal truism as it may seem, the fact that to be a chronic

³⁶ Thrall, J. H. ‘Prevalence and costs of chronic disease in a healthcare system structured for treatment of acute illness’ in *Radiology*, 2005 Vol. 235, No. 1, p. 9.

³⁷ *Ibid*, p. 10.

³⁸ Carel, H. *Illness: the cry of the flesh*, Acumen Publishing, UK, 2008, p. 80; For a good guide to the various ways that chronic disease can be defined see: Walker, C. ‘Recognising the changing boundaries of illness in defining terms of chronic illness: a prelude to understanding the changing needs of people with chronic illness’ in *Australian Health Review*, 2001, Vol. 24, No. 2, p. 209.

³⁹ Martin, C. M. ‘Chronic disease and illness care: adding principles of family medicine to address ongoing health system redesign’ in *Canadian Family Physician*, 2007, Vol. 53, No. 12, p. 2086.

illness one must have it for a long time is still a claim that needs examining. This is because what may be chronic now may not be so in the future, or may overlap with something regarded as acute. Consider, for example, that you are unfortunately involved in a car crash, which does severe damage not only to your insurance premiums but also to your back, breaking your spine in several places. This leads to a week in hospital, followed by many return visits, orthopaedic and physiotherapy sessions and at first a total change to your home environment. Gradually you stop feeling so much pain when you walk, are able to lift things again and bit by bit reestablish a normal life. Within 18 months you are able to play sport again and are looking to lose the weight you gained whilst sitting idle in convalescence. The whole process has taken longer it takes some people to endure breast cancer treatment, and yet breaking bones is very much considered an acute medical emergency whereas cancer is normally defined as chronic.⁴⁰

Perhaps that example was unfair. After all, is a spinal injury the same thing as a long-term disease? Its properties are certainly similar to many acute conditions: an external shock which destabilises the body; either self-limiting or fatal; there are medical interventions which aid the recovery of previous or near-previous functioning. The point is possibly not whether breaking your back is comparable something like myocardial infarction, but rather to demonstrate that simply lasting a long time is not a strong enough demarcation to completely separate 'chronic' conditions from the rest.

It is also important to recognise that what might appear to be a chronic disease today may well be an illness which at some point in the future comes to be considered otherwise. For example, syphilis is now easily treated by antibiotics. However, it once was a condition which could progressively degenerate a patient over decades, leading to mental and physical decay and ultimately death. For most in

⁴⁰ This last point is debatable: some cancers are aggressive enough that they only last a short period of time, and it is true that historically cancer was not considered a chronic illness.

the developed world it has become little more than an embarrassment and an inconvenience, certainly not a morbid threat. It seems fairly straightforward to argue that syphilis, and many other diseases, were once chronic but are now acute, and that these categories are as dependent on our ability to treat diseases as the properties of the disease itself. Or at least it does if we are only taking into account time-span.

Are there other factors then which we should contemplate when deciding what constitutes a chronic disease? Should the classification in actual fact be independent of medical responses, and instead essentialist? If so, then an acute disease would arguably become one which either kills or gets killed, lasts a short period of time and comes on quickly; it is unable to coexist with a body that functions, even in a limited capacity. Under this reading acute diseases then possess something of an odd duality, being either that which is fairly deadly or that which is almost harmless.⁴¹ Syphilis here returns to its life as a chronic illness, but one whose true calling is snubbed out by pharmaceutical intervention. Chronic diseases in this view become those which are nonself-limiting, those whose reoccur frequently, those that the body cannot expel. Those that do indeed last a long time.

This view suffers from an implicit assumption that within diseases there are natural kinds which can help us distinguish between the chronic and the acute.⁴² The simplicity of this approach ignores the many complicated ways in which disease interacts with individuals, and interacts with them differently, as well as for the most part disregarding the effects of medical intervention. Because of this, I believe that if we are to construct a definition of chronic diseases which is useful and accurate, *here and now*, then we must disregard or at least downplay essentialist elements. We

⁴¹ That is to say, an entity that kills you or is killed by you in short order.

⁴² Alongside the charge that there are plenty of ambiguous counterexamples which seem to provide a compelling argument for grey areas: brain damage for instance, or infectious short term diseases which leave you chronically affected like, say, the scarring from severe scabies or polio which leaves you paraplegic.

must also ask how much strain we intend to put on our concepts, and whether our descriptions can take such a load.

In this case, I do not believe it to be unreasonable to expect that a pragmatic demarcation of 'chronic' from 'acute' is possible, especially if it is tied to a specific set of conditions which are to be examined. It may at first seem as though I am skirting around the point to ask the following questions, but taken together I think they give a fairly good account of what a chronic disease might look like and entail:

does the disease necessitate repeated medical visits, continual medication or other treatment? - is it talked about in months and years or days and weeks? - is 'normal life' for the patient altered on a permanent or semi-permanent basis? - is major adaptation required, does the condition alter the sufferer's sense of self and body? - is the disease something that is being managed rather than fought, delayed instead of cured? These questions are not intended to create a watertight definition of chronic diseases, but they do provide us with a starting point for discussing the topic which does not rely entirely on time-span or essentialism and draws a picture of chronic illness which many patients would recognise.

I now return to what I wrote at the beginning of this section, namely that chronic conditions 'live within the crux of many philosophical problems'. Overriding philosophical ideas - how we view the body and the nature of disease - clash with chronic illnesses which contradict our prior beliefs about disease. Arthur Frank, in his excellent book *The Wounded Storyteller*, confronts this dissonance narratively.⁴³ Frank explains that people tend to talk about their diseases in ways which either conform or confront our expectations of what an ill person should be like. The most common attitude and method of communicating as a sick individual is termed the 'restitution narrative', that is, the story of a person who has recently become ill but is trying to, and will, recover soon. Think, for example, of commonplace 'battle' narratives as they relate to cancer: people win their war with the

⁴³ Frank, A. *The Wounded Storyteller*, 2013, University of Chicago Press, USA.

disease or they lose their brave fight, or else they hang in there whilst medicine attacks the condition, hoping to become survivors. Frank writes that ‘contemporary culture treats health as the normal condition that people ought to have restored. Thus the ill person’s own desire for restitution is compounded by the expectation that other people want to hear restitution stories’.⁴⁴

For Frank the central assumption of the sick role is that people take it up in the belief (both of themselves and others) that they will get better - or at least continue to have faith that they will - and it is this understanding of disease which gives restitution stories their narrative power. However, in case of many chronic illness, these narratives no longer fit, and in the place of restitution we are left with ‘chaos’: an unending, spasmodic and unordered view of what is happening. This creates its own problems as it rubs uneasily against the form that doctors and others expect a patient to take: ‘clinicians cannot entertain chaos because chaos is an implicit critique of the modernist assumptions of clinical work’.⁴⁵ In the end, the sick are left in uncomfortable state where storytelling - the way that they understand what is happening to them and express it to those around them - breaks down entirely, and this collapse is ‘compounded by other people’s resistances to non-restitution stories of illness’.⁴⁶

The problems often faced by chronically sick people highlight philosophical points about existing models of disease. These conditions often fail to fit into conventional understandings of illness and illustrate the futility of both our common narrative responses and of medical intervention (though only if medical intervention’s primary aim is to cure, to end).

Clinically, research indicates that large numbers of chronically ill patients are not happy with the care they receive, and that they do not receive enough or the right

⁴⁴ Ibid., p. 77.

⁴⁵ Ibid., p. 111.

⁴⁶ Ibid., p. 191.

kind of assistance.⁴⁷ There is some evidence to suggest that when the condition is limiting (i.e. the individual's social, personal and economic activity is restricted by their illness), then this dissatisfaction is greater.⁴⁸ My own research (to be discussed in Chapter IV) would also seem to support these claims.

Literature on this topic is regrettably sparse in some areas. Whilst an excellent sociological tradition exists, from Kleinman to Charmaz, characterised by a devotion to compassionate, humane writing, there is a lack of philosophical work on the subject, something both striking and worrying.⁴⁹ Many writings attempt to formulate or critique theories of disease in general, and as such touch on chronic illness incidentally, but few regard it as something that might pose unique problems. One exception exists in von Engelhardt, whose work attempts to situate the experience of chronically ill patients in a broader philosophical context. His argument is that chronic disease generates unique stress and puts demands on interpersonal relationships which mean that 'concepts of health and disease require new definitions'.⁵⁰ He goes on to say that philosophers are capable of 'producing valuable interpretations of health and disease that [take] the spiritual or cultural nature of human experience into account, [and question] the established positivistic perspective'⁵¹. It is time, he is saying, to broaden our writings about chronic disease

⁴⁷ Wagner, E. H. 'Chronic Disease Management: what will it take to improve care for chronic illness?' in *Effective Clinical Practice*, 1998, Vol. 1, No. 1, pp. 2-4; Darker, C., Casey, E., Seraukina, T., Whiston, L. and O'Shea, B. *The Patients' Perspective: A Survey of Chronic Disease Management in Ireland*, Report, Department of Public Health and Primary Care, Trinity College Dublin, 2014.

⁴⁸ Hewitson, P. *et al* 'People with limiting long-term conditions report poorer experiences and more problems with hospital care' in *BMC Health Services Research*, 2014, Vol. 14, No. 33, <http://www.biomedcentral.com/1472-6963/14/33>.

⁴⁹ Charmaz, K. *Good Days, Bad Days: The Self in Chronic Illness and Time*, 1993, Rutgers University Press, USA.

⁵⁰ von Engelhardt, D. 'How to support the patient with chronic disease. A philosophical point of view' in *Journal of Nephrology*, 2008, Vol. 21, No. 13, pp. 27-28.

⁵¹ *Ibid.*, p. 28.

and recognise that though biomedicine is astonishingly successful at keeping people alive, what we often fail to reflect on is ‘the quality, or lived experience, of these many lives that have been saved’.⁵²

I think that this (von Engelhardt’s) point is key: illness is a topic ripe for philosophical reflection, but chronic disease in particular leads us to question our assumptions around sickness and well-being, precisely because it is not accommodated as well (or in some cases, at all) by the metaphysical guide ropes we use to understand medical conditions.⁵³ When he says that the concepts of health and disease need new definitions, he is recognising the inadequacy of our current frameworks when it comes to providing insight into certain types of diseases, and it is this inadequacy I will be highlighting and challenging throughout this thesis.

Returning to chronic illnesses, it should be noted that they can also be viewed as an issue of social justice. The way that patients are treated raises serious questions about the distribution of resources within health infrastructure. Those with long-term conditions who suffer the most, outside of their symptoms, are those who are least able to materially support themselves, whether that involves paying for regular medication, hiring carers, modifying their living space or other costs associated with illness. Many are forced to continue working under great bodily distress because the alternative is homelessness and destitution. This is especially apparent in a health care system such as the US’s, where providing assistance for the chronically ill is not incentivised and therefore underprovided.⁵⁴ Often the need for more material capital is accompanied by an increased reliance on a social network that

⁵² Brennan, J. ‘Transitions in health and illness: realist and phenomenological accounts of adjustment to cancer’ in Carel, H. and Cooper, R. (eds.) *Health, Illness and Disease*, Acumen Publishing, UK, 2013, p. 129.

⁵³ Havi Carel has written extensively on the value of illness to philosophy (and vice versa). See, for example: Carel, H. ‘The Philosophical Role of Illness’ in *Metaphilosophy*, 2014, Vol. 45, No. 1, pp. 20-40.

⁵⁴ Walker, C. 2001, p. 211.

can offer help if not always understanding. Thus the weaker a person is connected to others or integrated into such a network at the time of their illness, the more likely they are to struggle with the resulting financial, physical and psychological effects. Havi Carel has written about how the social world of patients, 'so crucial to happiness' can shift and morph as chronic illness wears on. She writes that 'relationships come under new kinds of pressure when the autonomy and independence of the ill person are modified. Old friendships must change to accommodate the illness or eventually wane. New friendships are now formed in the shadow of illness'.⁵⁵

What Carel does not mention in the extract above (though does discuss elsewhere) is how much of this disheartening recalibration of social networks is dependent upon having a strong web of friends and colleagues in the first place, no matter how distressing it is to watch your grip on such relationships loosen or disintegrate. Later on in this work we will be introduced to individuals whose life was hard and isolated before illness, after which they unfortunately in some cases were left almost totally alone. In short, it is those on the fringes of society, those already perhaps marginalised socially and economically from the benefits of living in a developed countries, who find themselves worse off should they develop a chronic disease.⁵⁶

I hope that by now it is clear that despite the inherent vagueness of the concept, there is enough that is substantive about chronic disease to make it relevant as a topic of philosophical inquiry. I wish to use chronic illness in this thesis as a way of demonstrating that there are a multitude of ways that people experience sickness which are not adequately predicted or encapsulated by our expectations of disease.

⁵⁵ Carel, H. 2008, p. 74.

⁵⁶ It should also be noted that those individuals who are marginalised economically and socially tend to live both shorter lives and lives in which more time is spent in poor health or with a disability: Marmot, M., Allen, J., Goldblatt, P. *et al* 'Healthy Lives, brighter futures - the strategy for children and young people's health', Marmot Review Team, UK, 2010.

Within chronic illness, there are a set of conditions, held loosely together, that more than any others exemplify this problem. These are termed 'contested illnesses' and it is to them that I turn now.⁵⁷

At first glance, it might seem that there are so many ways that a disease could be considered 'contested' that describing one as such becomes virtually meaningless. Although this is true to an extent, I would like to demonstrate in this section that it is possible to demarcate contested illness in a meaningful way. The conditions I am after are figures of doubt in their entirety - the type of contestation that occurs is fundamental not specific. They are illnesses that appear to us not as controversial because we don't know their exact mechanism or which drugs are most effective at treating them but because in some sense we suspect them to *not exist*. They are, in my terminology, *ontologically* contested. But first, in what ways might a disease be considered contested and why are these criteria often inadequate in the making of a bona fide contested disease?

Illnesses can be disputed clinically, pharmaceutically and legally, with arguments often springing up regarding aetiology and risk factors as well. Politically too, they can be contested and there have been well known and large-scale campaigns around individual illnesses. These focus on changing perceptions of a certain disease, altering the tone of education, improving access to resources, information and infrastructure. A side-effect of these initiatives is that often disenfranchised patients feel like they have been able to recover some dignity and achieve a form of moral reconciliation with a society that has stigmatised and marginalised them. The patient response to the AIDS crisis in the 1980s is almost the epitome of this kind of political contestation, though equally the work of disabled activists, the

⁵⁷ Some examples of contested illness include fibromyalgia, chronic fatigue syndrome, chronic lyme disease, toxic mould syndrome, sick building syndrome, multiple chemical sensitivity and silicone breast implant disease.

blind and the deaf movements as well as women's health campaigns could be included here.⁵⁸

The way that doctors think we should respond to diseases is another source of conflict. For any given condition there exists a spectrum of medical options. Different treatment programmes are often favoured and promoted across different localities, between individual hospital departments and by doctors themselves, a process which reflects the fragmented, specialised nature of modern medicine. If alternative remedies are taken into account then it becomes clear that for any condition there exists a plurality of possible medical reactions, not all of which could be considered complementary. Yet this is considered fairly ordinary and offering patients choice is not framed as contestation.

Pharmaceutically, diseases are contested in the sense that a complex relationship has emerged in some countries, most notably the US, between the drug companies, doctors and patients. I separate this from the clinically arguments discussed above because often this conflict comes to be about more than simply the 'best' way to treat a specific condition. The growth of behavioural disorders and fears of over-diagnosis and medicalisation are good examples of where illnesses become pharmaceutically contested, the arguments being centred around the administration of

⁵⁸ Much has been written about the politicisation of AIDS, a good place to start being Epstein, S. *Impure Science: AIDS, activism, and the politics of knowledge*, 1996, University of California Press, USA; for an examination of how the deaf community interacts politically with social changes see Lane, H. *The Mask of Benevolence: disabling the Deaf community*, 1999, DawnSignPress, USA; for many of these examples it may seem as though the key battles are over responses to illness - in other words what to do about them. This is certainly a part of what goes on, but it is important to remember the conflict over meaning that occurs, whether it is the fashioning of AIDS as a disease caught only by 'deserving', 'depraved' individuals or deafness as an exclusionary disability.

drugs and explaining both the supply of and demand for such treatments.⁵⁹

Related to the sometimes murky clinical and pharmaceutical picture, many diseases could be considered to be aetiologically contested. This terminology is loose, but its basic essence is easy to discern: how exact and numerous are our explanatory models? Do different descriptions of potential causality compete in the academic space for legitimacy? It is clear that having a full aetiological picture is no prerequisite for diagnosis, prognosis or treatment. Autoimmune diseases are a case in point of this kind of conflict, as discussions around aetiology remains speculative and varied.⁶⁰ Even when considering diseases whose mechanism or causes we have known for some time, it should be noted that research is constantly being undertaken to expand our understanding. Many common conditions, whose clinical features have been recognised for some time, have only relatively recently begun to be understood more fully from an aetiological standpoint and often their histories are ones of treatment before understanding, or indeed treatment on the basis of false understanding.⁶¹

Legally, diseases have become central to fights over dismissal from work, welfare access and compensation. Employment rights were rapidly expanded during the

⁵⁹ David Healy has written extensively about this topic (see, for example: Healy, D. *Let Them Eat Prozac*, 2004, New York University Press, USA and Healy, D. *Pharmageddon*, 2012, University of California Press, USA); Christopher Lane also covers this problem well in Lane, C. *Shyness: How Normal Behaviour Became a Sickness*, 2008, Yale University Press, USA; it has been conceptualised in various critical ways by other authors, such as Goldacre, B. *Bad Pharma: How drug companies mislead doctors and harm patients*, 2012, Fourth Estate, UK; Elliott, C. *White Coat Black Hat: Adventures on the Dark Side of Medicine*, 2011, Beacon Press, USA; González-Moreno, M., Saborido, C. and Teira, D. 'Disease-mongering through Clinical Trials' in *Studies in History and Philosophy of Biological and Biomedical Sciences*, 2015, Vol. 51, pp. 11-18; for a short overview of this process, see Cooper, R. 'Disease Mongering' in *The International Encyclopaedia of Ethics*, 2013, published online.

⁶⁰ Alzabin, S. and Venables, P.J. 'Etiology of autoimmune disease: past, present and future' in *Expert Review of Clinical Immunology*, 2012, Vol. 8, No. 2, pp. 111-113.

⁶¹ For example, see Clarke's discussion of the history and aetiology of cervical cancer: Clarke, B. 'Causation in Medicine' in Gonzalez, W.J. (ed.) *Conceptual Revolutions: from Cognitive Science to Medicine*, 2012, Netbiblo, Spain.

20th century, and part of this process was the acknowledgment that work environments can make people sick, that sometimes people are too sick to work and that this 'right to be sick' needs to be protected and legislated for.⁶² However, given the clear conflict of interest here between the state, employers and the individual, it is inevitable that vigorous and lengthy legal battles can and do ensue. Often what is under scrutiny is the legitimacy of symptoms, the extent to which they disable and the degree to which prognosis of the condition suggests functional limitation. The reason for this brief exposition of the various ways in which aspects of disease can be contested is to illustrate the simple point that a condition may be disputed in some or even most of the ways above and *still not be considered a 'contested illness'*. There is a further jump that must be taken in order for a disease to become contested, which is hard to precisely quantify, but involves a composite of the above which lead the medical community and society at large to fundamentally doubt the condition in an ontological sense. It is this questioning of *being* which I have taken to be the hallmark of a contested disease. How can we develop this definition?

Swoboda's definition

A good place to start is to look at the work of Swoboda, who provides the following five points as key features of contested illnesses:⁶³

- 1) Their aetiologies are ambiguous;
- 2) their existences are linked to other diagnoses and co-morbid conditions;

⁶² Not to say that there are no examples from earlier centuries, see Schivelbusch, W. *The Railway Journey: The Industrialization of Time and Space in the Nineteenth Century, With a New Preface*, 2014, University of California Press, USA, pp. 134-149.

⁶³ Swoboda, D. A. 'Embodiment and the Search for Illness Legitimacy Among Women with Contested Illnesses' in *Michigan Feminist Studies*, 2005, Vol. 19, Issue Title: 'Bodies: Physical and Abstract', p. 73; I have changed the order for clarity, in the original, number 5 was placed first.

- 3) their treatment regimens are unclear;
- 4) their legal, medical, and cultural classifications are disputed;
- 5) their statuses as legitimate illnesses are highly controversial.

Taken together, this schema is useful for understanding how a condition comes to be considered a disputed illness. What is perhaps unclear is how some diseases can be said to fulfil numbers 1-4 without necessarily entailing that the fifth condition becomes a feature of the illness. How is it that an illness becomes or is contested in all four of the ways mentioned above but does not lose its status as a legitimate illness? And if we establish that the first four criteria are not necessary for describing a contested illness, then surely what we are left with is simply a tautology?⁶⁴ In this section I will approach these questions with a mind to revising Swoboda's list to more accurately capture the key components of disputed, or as I have phrased it, ontologically contested diseases.

To explore this, let us take two examples - asthma and chronic fatigue syndrome (CFS) - and discuss why one is ontologically contested and the other is not with reference to the above formulation. Asthma is chosen here as superficially it fulfils much of the criteria above, and yet remains emphatically not a contested disease. CFS is, however, very much considered to be a contested illness, and the following discussion should hopefully clarify why it is rendered such whilst asthma is not.

CFS presents significant diagnostic and professional challenges for healthcare providers. Patients complain of tiredness, lethargy and dangerously low levels of energy. Cognitive difficulties appear simultaneously; forgetfulness and difficulty focusing through to severe migraines and depression. Exercise is painful and can often lead to lengthy recovery periods of forced inactivity and musculoskeletal pain. These symptoms ebb and flow and change day to day, but rarely disappear entirely.

⁶⁴ i.e. a contested disease is defined by its status as a legitimate disease being highly contested.

There appears to be no abnormality in standard clinical indicators of illness: blood pressure, blood sugar and heart rate don't appear to correlate, clinical examinations proffer no results, CAT scans likewise. Overall, it is extremely difficult to diagnose CFS in any orthodox manner, and it is normally classified as a diagnosis of exclusion, that is, arrived at after other possibilities have been eliminated. The criteria generally used require persisting fatigue for at least 6 months which is not explained by other medical or psychiatric conditions and is not alleviated by rest.⁶⁵

To return to Swoboda's criteria, we can note immediately that the aetiology of CFS is unclear. However, the same could be said for asthma. Causal models that deal with asthma tend to focus on highlighting prenatal, childhood, environmental and genetic risk factors which relate to a higher incidence of the condition developing. These include firm links such as maternal smoking, family history and environmental pollution and weak links such as exposure to allergens, diet and nutrition, stress levels and breastfeeding.⁶⁶ This being said, all factors are sufficient and not necessary. Overall, the aetiological picture is stubbornly multifarious and despite a large amount of research it is difficult to discern clearly *what causes asthma*. CFS also has no universally accepted aetiology, but rather numerous conceptual models based around physiological, psychosomatic and psychological

⁶⁵ Fukuda, K. 'The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group' in *Annals of Internal Medicine*, 1994, Vol. 121, No. 12, pp. 953-959; for a list of tests that should be completed before a CFS diagnosis is arrived at see NICE: *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy)*. *Diagnosis and management of CFS in adults and children*, 2007, National Institute of Clinical Excellence, London.

⁶⁶ Subbarao, P., Mandhane, P.J. and Sears, M. R. 'Asthma: epidemiology, etiology and risk factors' in *Canadian Medical Association Journal*, 2009, Vol. 181, No. 9, pp. 181-190.

frameworks.⁶⁷ It differs from asthma however, in the sense more moral onus is put on the various causal explanations. The conflicts that exist tend not to be scientific discussions about the importance of this or that influence on the condition, but represent a more dogmatic, factional process.⁶⁸ Many patients strongly reject all models which identify psychosomatic or psychological factors as primary agents, arguing that what they are suffering from must be organic. The implication here is that if their condition is not organic then the twin spectres of control and responsibility come into focus: the supposed control of symptoms and the subsequent responsibility for them.

What is different then, is that to CFS patients, the contested aetiology of their condition has ontological consequences in a way which the causal relationships behind asthma do not. This is because in the case of CFS, the aetiology exists in an explanatory void - it is a conflict about the existence of evidence, rather than what the evidence means. Doctors cannot say with confidence what causes either condition, but with asthma this ignorance is buttressed by various smaller pieces of knowledge: it is like we have most of the puzzle pieces but can't put them together to form the complete image. Determining the aetiology of CFS is a far less certain exercise, and the lack of substantive evidence one way or the other contributes to suspicions that without casual links of some kind we should question whether we are looking at a disease *at all*. From this short comparison it seems that the Swobo-

⁶⁷ The NHS list 6 possible causes for Chronic fatigue, see <http://www.nhs.uk/conditions/chronic-fatigue-syndrome/pages/causes.aspx> archived on 19/07/17 at <http://www.webcitation.org/6s5DPrQET>; for a more holistic overview see Tveito, K. 'So many things we do not know' in *Tidsskr Nor Lægeforen (Journal of the Norwegian Medical Association)*, 2014, Vol. 11, No. 134, pp. 1117-1118.

⁶⁸ That is to say, groupings of researchers, activists and patients congeal around different causal explanations, not always on the basis of the best available evidence. Certainly it seems in some cases at least models are preferred because of their acceptability to the social or psychological prejudices of the person preferring them rather than anything that could be considered scientifically compelling. The reasons for this are complex, and since a very similar process occurs in the case of fibromyalgia, I refer you to Chapter IV for a more thorough discussion.

da's first condition needs to be modified or expanded to take into account variations in the types of aetiological ambiguities that are present.

Her second condition - that contested illnesses are linked to other diagnoses and co-morbid conditions - again appears to apply to both asthma and CFS. The former has long been known to be strongly associated with and in some cases exacerbated by many other conditions. In two separate, recent reviews, a high number of comorbid conditions were identified, including rhinitis, gastroesophageal reflux disease, bronchitis, atherosclerotic cardiac disease, psychopathologies and numerous others.⁶⁹ The precise relationship between these conditions is important to clarify as they can often obscure diagnosis and make treatment more difficult. Establishing links between other diseases and asthma has consequences for patients but also for public health policy.

CFS is also known to have a high comorbidity with other diseases. Fibromyalgia, irritable bowel syndrome, multiple chemical sensitivity, interstitial cystitis and psychiatric conditions such as depression and anxiety disorders have all been found in high prevalence amongst CFS patients.⁷⁰ The way that these conditions interact and influence each other is unknown, and again highly disputed by patients in a way that is unique to contested illnesses. For example, many CFS sufferers would argue that depression is a result of their debilitating fatigue, whereas researchers often posit that this connection is actually the inverse, or that both stem from the same source. Asthma patients do not have such a hostile relationship to their comorbidities.

⁶⁹ Boulet, L. and Boulay, M. 'Asthma-related comorbidities' in *Expert Review of Respiratory Medicine*, 2011, Vol. 5, Is. 3, pp. 377-393; Ledford, D. K. and Lockey, R. F. 'Asthma and comorbidities' in *Current Opinion in Allergy and Clinical Immunology*, 2013, Vol. 13, No. 1, p. 80.

⁷⁰ Aaron, L. A. *et al* 'Comorbid Conditions in Chronic Fatigue: A Co-Twin Control Study' in *The Journal of General Internal Medicine*, 2001, Vol. 16, No. 1, pp. 24-31; Denise, E. J. *et al* 'Conditions comorbid with Chronic Fatigue in a Population-Based Sample' in *Psychosomatics*, 2012, Vol. 53, No.1, pp. 44-50.

The crucial point here is that whilst asthma is associated with mostly 'organic' conditions, CFS finds itself entangled in a web of other contested illnesses or psychiatric diseases. In fact, the one comorbid feature of asthma that is resisted more than any other by patients is the suggestion that there are psychosomatic elements to the disease, hence literature which urges a careful and sensitive approach to the topic.⁷¹ Also notable is that the Global Initiative for Asthma (GINA) lists numerous factors which contribute to the development of asthma but only notes that emotional stress and psychiatric conditions can exacerbate the disease.⁷² This is in contrast to the ICD-10, which places psychological and behavioural causes alongside organic and environmental ones, indicating that there is a slight discrepancy between the medical view and patient outlooks.

So to look again at the criteria, it seems in this case that expansion of the second point is also necessary. What is important is not so much that comorbidities exist, but the types of connections that the condition has with other diagnoses and the perceived validity of those diseases. Especially relevant here is the question of psychiatric and psychosomatic disorders: if it appears that an illness is mostly associated with these types of diseases then I suggest that it will in turn be more likely to be considered contested.

The third feature under discussion here is that in general the treatment regimes of disputed illnesses are unclear. In this case it seems that there is more of a dichotomy between my two examples. Whilst the treatment of asthma has certainly changed historically, and different approaches have their benefits, it is generally accepted that in most cases we can now manage the symptoms effectively in wealthy

⁷¹ Muramatsu, Y. *et al* 'Bronchial Asthma: Psychosomatic aspect' in *The Journal of the Japan Medical Association*, 2001, Vol. 126, No. 3, pp. 375-377.

⁷² Moes-Wójtowicz, A. *et al* 'Asthma as a psychosomatic disorder: the causes, scale of the problem, and the association with alexithymia and disease control' in *Pneumonologia i Alergologia Polska*, 2012, Vol. 80, No. 1, p. 14.

nations both in acute emergencies and in the long term.⁷³ There would appear to be very little that is 'contested' about this.

CFS presents far more significant challenges for doctors and patients, as very few treatments have been found to have any consistent effect on those with the illness. A plethora of different ideas and potential cures have been suggested, and many patients attempt various regimes, largely without success. Responses to treatment are extremely idiosyncratic - what works for one rarely works for another - and those with CFS can grow pessimistic over time as to the effectiveness of any new programme that is suggested to them. Attempts to relieve symptoms such as chronic pain likewise suffer from inconsistent patient response which makes it difficult to draw conclusions across the whole condition.

Two controversial treatments have been fairly widely touted as having therapeutic benefits for CFS patients: cognitive behavioural therapy (CBT) and graded exercise therapy (GET). Part of the justification for using these strategies is that over time patients' cardiovascular and muscular strength deteriorates due to inactivity, which contributes to maintaining fatigue symptoms. Both methods attempt to restore physical strength gradually and combat unhelpful views about the disease and the dangers of exercise. These treatments have not been shown to help all patients, but

⁷³ Asthma UK describes the medication available for patients as 'incredibly effective' (<https://www.asthma.org.uk/advice/inhalers-medicines-treatments/> archived on 19/07/17 at <http://www.webcitation.org/6s5DyzZ1p>). Severe problems persist in countries where patients cannot access treatment, and the number of patients has increased rapidly over the last few decades due to population growth, urbanisation, increased pollution levels and other factors: Asher, I. and Pearce, N. 'Global burden of asthma among children' in *The International Journal of Tuberculosis and Lung Disease*, 2014, Vol. 18, No. 11, pp. 1269-1278.

it has been argued that in a significant number of cases they can be effective.⁷⁴

However, among some patients and a select band of researchers, these approaches are often rejected because they rely on a psychosocial model of illness that they disagree with. GET has also been argued to cause damage to patients through over-exertion. The flagship study which promoted its benefits as a treatment regime - known as the PACE trial - has been criticised heavily in what became an ongoing and acrimonious dispute.⁷⁵

In this case, simply stating that 'treatment regimes are unclear' misses the most important aspect of this. It is not just that they are unclear, it is that they are inconsistent and largely impotent. If we think of a disease like multiple sclerosis (MS), per-

⁷⁴ For example see: Wallman K. E., Morton A. R., Goodman C., Grove R., Guilfoyle A. M. 'Randomised controlled trial of graded exercise in chronic fatigue syndrome' in *Medical Journal of Australia*, 2004, Vol. 180. pp. 444–448; Whiting P, Bagnall A. M., Sowden A. J., Cornell J. E., Mulrow C. D., Ramirez G. 'Interventions for the treatment and management of chronic fatigue syndrome: a systematic review'. *The Journal of the American Medical Association*, 2001, Vol. 286, pp.1360–1368; Price, J. R., Mitchell, E., Tidy, E. and Hunot, V. 'Cognitive behavioural therapy for chronic fatigue syndrome in adults' in *Cochrane Database of Systematic Reviews*, 2008, No. 3, Art. No.: CD001027. DOI: 10.1002/14651858.CD001027.pub2.; White, P. D. *et al* 'Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial' in *The Lancet*, 2011, Vol. 377, No. 9768, pp. 823-836.

⁷⁵ *Ibid.*; for an example of the critical response to this type of treatment plan see, from a patient organisation: http://www.mecfswa.org.au/Treatment/CBT_and_GET archived on 19/07/17 at <http://www.webcitation.org/6s5E7UY32> or this literature review (note however that the credibility of both journal and researchers is questioned in this case): Twist, F. N. M. and Maes, M. 'A review on cognitive behavioural therapy (CBT) and graded exercise therapy (GET)' in myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS' in *Neuroendocrinology Letters*, 2009, Vol. 30, No. 3, pp. 284-299; for a critique of the PACE study specifically, see Wilshire, C., Kindlon, T., Matthees, A. and McGrath, S. 'Can patients with chronic fatigue syndrome really recover after graded exercise or cognitive behavioural therapy? A critical commentary and preliminary re-analysis of the PACE trial' in *Fatigue: Biomedicine, Health and Behaviour*, 2017, Vol. 5, pp. 43-56; for a further selection of the critical dialogue surrounding the PACE trial, see <http://www.virology.ws/mecfs/> archived on 19/07/17 at <http://www.webcitation.org/6s5EN5qnR>.

haps more suitable for comparison here than asthma, then what we see is a condition that debilitates, destroys, and is ultimately unmanageable in a way that asthma isn't. However, vast therapeutic interventions exist for MS which can manage symptoms, slow progression and aid recovery from attacks. The aetiology of MS remains unknown, but its symptoms *can* be effectively treated, if you allow that treatment doesn't always have to involve total alleviation of distress or some kind of restoration to pre-disease health. Within the parameters of the disease, we can do more to help those diagnosed with MS than we can for their CFS counterparts and this is I think where treatment contributes to the ontological doubt surrounding the disease.

Swoboda's fourth point is that contested illnesses' 'legal, medical, and cultural classifications are disputed'. It is not immediately clear what is meant by this but I think that what she is arguing is that the way the disease is represented, talked about and assumed by many *to be*, is in constant flux between interested groups. Whether or not this can be said with confidence to be the case with asthma is uncertain.

Asthma no doubt intersects the legal system at certain points, though less than many other conditions. It is rare, but not unheard of, for individuals to be discriminated against for their condition, and there is a smattering of unfair dismissal cases reported in the press.⁷⁶ Since asthma is largely a childhood disease, an important way that its legal 'classification' is contested is in relation to healthcare and welfare access, especially under insurance-based healthcare system such as the USA. Making sure that your child can get the care they need is often a legal issue, and links have been established between barriers to access, socio-economic status and men-

⁷⁶ For example: http://www.clarkslegal.com/Legal_Updates/Read/Employee_who_had_1_in_4_days_off_sick_wins_unfair_dismissal_claim archived on 19/07/17 at <http://www.webcitation.org/6s5ETeUwC> or <http://www.personneltoday.com/hr/asthma-suffering-bar-worker-wins-6000-for-disability-discrimination-and-unfair-dismissal/> archived on 19/07/17 at <http://www.webcitation.org/6s5EZnvv6>.

tal health of the families involved.⁷⁷ Also in the US, the vast majority of states have passed 'inhaler carry' laws, which entitle students to take prescription medicine on school premises and provide information for educational authorities.⁷⁸ The legal classification here is again based around access to resources.

Asthma has also featured in public health campaigns and attempts to improve workplace and public air safety. This has had success in reducing occupational asthma through the identification and eradication of harmful agents, contributed towards reducing pollution and had an effect on the second-hand smoke debate.⁷⁹ Overall however, it would be a stretch to say that asthma is understood legalistically beyond a minority of contexts, and as such its legal classification does not particularly figure as a ground for conflict. The legal work that surrounds asthma is certainly less acrimonious than that for CFS.

As discussed earlier, some medical aspects of asthma are shrouded in ambiguity, and to researchers it is a real aetiological puzzle. But whether or not this actually represents something that can be classified as a dispute is unclear. Asthma is regarded as fairly stable medically in a way that CFS is not, and I think this is the key factor here. Most diseases possess some kind of medical uncertainty, but that uncertainty does not always translate into conflict.

Culturally, it is easier to see how asthma might fit into the schema we are using. The cultural meaning of asthma has been for many years a case of crude stereotyping: asthmatics are routinely typified as the weak, sickly coward, unable to partake in physically or emotionally strenuous exercise without their trusty inhaler. Clark carried out a content analysis on 66 Hollywood films and discovered that by

⁷⁷ Wood, P. R. *et al* 'Relationships Between Welfare Status, Health Insurance Status and Health and Medical Care Among Children With Asthma' in *The American Journal of Public Health*, 2002, Vol. 92, No. 9, pp. 1446-1452.

⁷⁸ American Lung Association *A National Asthma Public Policy Agenda*, 2009.

⁷⁹ *Ibid.*; Centers for Disease Control and Prevention (CDC) *Best Practices for Tobacco Control Programs*, 2007.

far the two biggest standard representations of children with asthma were negative. Asthmatics were portrayed as a) socially different in a negative sense, i.e. a misfit of some kind, a nerd or a wimp, and b) that asthma is most often a stress response to a situation.⁸⁰ It should also be noted that there was a time when others were implicated in the production of asthmatic symptoms, namely over-protective, 'smothering' mothers whose concern for their child's health was argued to have become pathological.⁸¹

This strikes me as the only area in which the 'classification' of asthma could be said to be disputed, especially given the distance between the representations of the disease and its medical reality.

Looking at CFS, it is clear that it does indeed find its legal, medical and cultural classifications in a state of bitter negotiation. A large portion of the frustration and disappointment felt by CFS and other patients with contested illnesses is related to their perceived lack of legal rights. In areas of employment and welfare, sufferers consistently report finding themselves in the midst of a seemingly contradictory struggle: the struggle to prove themselves fit enough to work in order to stay employed and then the subsequent struggle to prove themselves ill enough to be entitled to state support should the first strategy fail.

Medically, it is difficult to analyse the current view of CFS without making reference to both the fairly wide-spread consensus of the profession that this condition

⁸⁰ Clark, C. D. 'Asthma episodes: stigma, children, and Hollywood films' in *Medical Anthropology Quarterly*, 2012, Vol. 26, Issue 1, pp. 92-115; a lesser-known archetype for asthma sufferers also exists: that of the individual determined to exert themselves *because* of their asthma rather than *in spite* of it. Che Guevara is one such example of an individual whose condition in part drove him to become more rather than less energetic, as part of a 'stubborn personal battle to beat asthma' (see 'Cuba: Castro's Brain' in *Time Magazine*, August, 1960). As a severely asthmatic child myself, my parents greatly encouraged me to swim and play other sports rather than trying to protect me through enforced abstention, so I recognise and appreciate this alternative model of the asthmatic.

⁸¹ Appignanesi, L. *Mad, Bad and Sad: A History of Women and the Mind Doctors from 1800 to the Present*, Viarago, UK, 2009, p. 351.

has psychosomatic elements and the equally wide-spread rejection of that consensus by patients. What is different about this kind of conflict is that far greater disagreements exist between patients and doctors than between different researchers discussing the aetiology, best treatment, etc., something which is made even more extraordinary when you consider the vague and underdetermined clinical picture. Cultural wrangling over the meaning of CFS has been explored by Hossenbaccus and White, who carried out a content analysis of medical publications, patient organisation websites and newspaper articles about the condition. They discovered, not to their surprise, a large discrepancy between patient organisations, of whom 89% represented CFS as an organic disease, and medical authorities, who tended to regard it as having both physical and psychological elements (63%). Media outlets were fairly split, 58% portraying it as a wholly physical condition. The imbalance present here gives us clear indicators as to the nature of the cultural dispute. Again it comes back to patients (or patient organisations) being strongly resistant to a psychological label (no matter what form it comes in) and medical researchers reaching for one out of a lack of alternative explanations.

There is another side to this cultural representation too, which is the prevalence of negative perceptions of CFS patients amongst doctors and wider society. In a recent study examining medical students' views of the disease, common prejudices such as sufferers being 'lazy' or sharing negative personality types, as well as being difficult patients, surfaced regularly amongst the participants.⁸² Largely, it appeared these views had been absorbed from superiors and media reports. Shorter suggests that this has always been the case, historically. He writes that 'knowing they were not facing organic disease, organically oriented physicians tensed up whenever they encountered chronic somatisers [patients whose bodies subconsciously converted

⁸² Stenhoff, A. L., Sadreddini, S., Peters, S. and Wearden, A. 'Understanding medical students' views of chronic fatigue syndrome: A qualitative study' in *Journal of Health Psychology*, 2015, Vol. 20, No. 2, pp. 198-209.

emotional distress into physical symptoms]’.⁸³ Individuals with contested illnesses also regularly report that these views are present amongst family members, friends and work colleagues. Unsurprisingly, patients try to fight these perceptions and wrestle the cultural meaning of their disease towards their advantage.

What I think needs to be made explicit in this discussion is that in large part the legal, medical and cultural classification of CFS emerges from medical uncertainty rather than from other sources. The identity of patients is not stretched and distorted because they belong to a persecuted minority, or because some powerful group has an interest in marginalising how they feel about their disease, it is altered because there is genuine scientific doubt about how to classify, explain and treat it, which in turn interacts with existing social beliefs about illness. This is not the case for asthma, and hence when we look at legal, medical and cultural classifications it is not enough to simply assert that they are in some way conflicted - we need to ask why they are considered in that way and what sustains the dispute.

By way of a short detour, it might be worth considering this discussion in light of research on uncertainty, stemming from the work of Donald MacKenzie and others in the 1990s.⁸⁴ The assumed relationship between expertise and confidence in a knowledge base - that those with the greatest access to information and experience in the field would be the most confident in both the facts of that discipline and the technology it produced - was convincingly shown to be oversimplified and in many cases wrong. Instead of a linear relationship, where uncertainty increased the further from the site of knowledge production, a different model was proposed whereby those closest to the beating heart of the field were more unsure and reluc-

⁸³ Shorter, E. *From the Mind into the Body: The Cultural Origins of Psychosomatic Symptoms*, 1994, The Free Press, USA, p. 24.

⁸⁴ MacKenzie, D. *Inventing Accuracy: A Historical Sociology of Nuclear Missile Guidance*, 1990, MIT Press, USA; MacKenzie, D. ‘The Certainty Trough’ in Williams, R., Faulkner, W. and Fleck, J. (eds.) *Exploring Expertise*, 1998, Palgrave Macmillan, UK; Wynne, B. ‘Uncertainty and environmental learning: Reconceiving science and policy in the preventive paradigm’ in *Global Environmental Change*, 1992, Vol. 2, No. 2, pp. 111-127.

tant to make strong claims than those from other, neighbouring disciplines. Those who were far away from the production of knowledge but for whom something was at stake could be expected to express the greatest degree of uncertainty.

That is to say that uncertainty exists in the first group, those actually conducting the studies and designing the technology, is minimised or ‘black boxed’ by the second, those who still work with it but not directly, and emphasised, focused on and potentially exaggerated by those furthest away who have a vested interest in magnifying the appearance of doubt.⁸⁵ Thus it is that those working directly on climate change or the relationship between lung cancer and smoking have a higher degree of suspicion in their causal models than the scientific community as a whole, but less than that which is relentlessly promoted by organisations and individuals who profit from a view of science that is socially constructed and fundamentally uncertain.⁸⁶ This final point, of something *being at stake* for some groups, is key to understanding this argument. In uncontentious areas of science, such ambiguity in knowledge production is less obvious because there is no-one who benefits from doubt. The line goes that climate change modelling on a planet other than Earth would look very different from what we are seeing today, because it would not exist in a social matrix containing organisations strongly invested in maintaining and expanding the infrastructures which contribute to man-made temperature increases.

It gets slightly complicated when we try to apply this to CFS, because we need to be careful not to conflate this certainty/uncertainty axis with the ambiguous/un-

⁸⁵ Bruno Latour developed the concept of a ‘black box’ over several books - see: Latour, B. *Science in Action*, 1987, Harvard University Press, USA; Latour, B. *Pandora’s Hope: essays on the reality of science studies*, 1999, Harvard University Press, USA.

⁸⁶ Oreskes, N. and Conway, E. M. *Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Global Warming*, 2011, Bloomsbury Press, UK; Following his groundbreaking work on exposing the uncertainty present in scientific knowledge production, Latour would lament his role in creating the situation described above: Latour, B. ‘Why Has Critique Run Out of Steam? From Matters of Fact to Matters of Concern’ in *Critical Inquiry*, 2004, Vol. 30, No. 2, pp. 225-248.

ambiguous scale I have been discussing.⁸⁷ That is to say, given that the ‘facts’ of CFS are themselves so tenebrous, speaking of certainty loses its bite somewhat: it may be that those related to the disease in some way are perfectly certain of its ambiguity across different measures (just as they may be perfectly uncertain of its unambiguity). However, what is useful is the both the idea that there is a three step variance in certainty as you move away from the position of greatest knowledge, and the idea that having something *at stake* is vital in understanding the motivations of those who seek to undermine the level of certainty attributed to a set of beliefs about a concept.

The first of these, the line of uncertainty, does not act in the same way as it appears to in other areas of contentious science. Insofar as you can chart uncertainty stretching from researchers in the field to GPs to patients (the three groups I feel most isomorphic with the general model), certainty levels vary between groups in relation to the supposed fact being discussed, with some drawing divergent responses and some producing a flat line of agreement.⁸⁸ This is predictable and explainable. What is of more interest is discussing what effect a vested interest - there being something at stake - might have on the levels of uncertainty.

It would seem, or it seems very much to me, as though the vested interests of all parties involved are in the direction of certainty about the unambiguity of CFS. Medical scientists want to understand what is going on, to be able to model the condition accurately and produce efficacious therapies; doctors want to be able to treat patients, to feel as though they have succeeded in their roles as healers; patients want to comprehend what is going on in their bodies, to be able to communicate that to those around them and, most of all, to get well. All of these groups would therefore benefit from a reduction in the ambiguity of CFS (whether that is

⁸⁷ Special thanks to Havi Carel for bringing this to my attention.

⁸⁸ Is CFS psychosomatic? Is CFS best explained partly or largely by reference to depression? Do symptoms get worse or better after short periods of exercise? Do anti-psychotics help patients?

framed as uncertainty about unambiguity or certainty about ambiguity) and none of those involved has any interest in promulgating the current view of CFS. But still we remain in a position of fairly widespread doubt as to the solidity of CFS - as a distinct condition, as a condition whose causality we understand, as an illness we can treat effectively. It therefore seems fairly convincing to me to posit that the ambiguity here is genuine and does not come about because of any vested interest one way or the other - that is to say the evidence that exists *genuinely* does not provide us with an adequate and reliable explanation for CFS, even to the standard of other (ambiguous but less so) aetiological frameworks.

I hope that this example has not been too exhaustive, but I also hope that it has gone some way to clarifying what makes a disease ontologically disputed. To summarise, below is a revised version of Swoboda's original criteria of contested diseases:

- 1) Their aetiologies are ambiguous: a solid empirical basis on which to determine between different speculative models is lacking; firm causal processes - mechanistic or probabilistic - are notable by their absence; diagnosis is likely from exclusion;
- 2) their existences are linked to other diagnoses and co-morbid conditions: mostly these themselves will struggle with 'legitimacy', they will be psychiatric or psychosomatic in nature, rarely will a clear relationship with an established organic disease exist;
- 3) their treatment regimens are unclear; effective treatments are difficult to find; highly inconsistent results are reported amongst patients;
- 4) their legal, medical, and cultural classifications are disputed: there exist discrepancies along these lines between patients and the medical community/society at large; this emerges from genuine scientific doubt and uncertainty, not prejudice;

Therefore:

5) their statuses as legitimate illnesses are highly controversial and they should be considered ontologically contested diseases.

Whilst I am confident that my attempt at definition above is successful to a greater degree than previous efforts, it is definitely open to the charge of being an overly descriptive, socially-determined account, one that fails to provide what could be termed a statistical essence - biomedical markers, tests, 'objective' pathology.⁸⁹ This critique would somewhat miss the point, in that it is precisely the absence of such things that leads to a disease being categorised in this way in the first place. I would therefore dismiss that argument as an overly naturalistic view of disease, something that will be elucidated in greater detail in Chapter II.

But what about the following scenario: a virus is discovered tomorrow that accounts fully and consistently for the symptoms of CFS, and as a result much of what has been discussed becomes instantly irrelevant, and the disease shifts into one of the many preexisting categories of illness that we are familiar with. This, though highly unlikely, could happen, but if it did I do not think it would prove too problematic for my categorisation. Firstly, our understanding of disease constantly changes in light of new information and it is not difficult to find examples of this in recent history. A disease shifting from one group to another, or groups fundamentally changing, is not a strong criticism of holding belief in the utility of those groupings given available information.

Secondly this example presupposes that the only adequate categories are those which are unchanging and stable through time. Not only would it actually be difficult to find completely stable biomedical categories, but there is also nothing wrong with a description that applies in a completely satisfactory manner now but may

⁸⁹ And of course, sociologists might contend the opposite, that it is *too* essentialist.

not at some point in the future.

Overall, it seems that despite problems, we can demarcate chronic, contested illnesses with some success. In doing so, we are able to establish a category of diseases which in many ways highlight our assumptions and open our eyes to medical and social challenges.

Malingering, validity and legitimacy

Patients with chronic, contested illnesses often face accusations of insincerity, of faking or exaggerating symptoms for gain and sufferers report being labelled malingerers. As we shall see, it can be unclear exactly what this entails conceptually. What is not unclear is that as a result they feel like their experience is invalidated and their disease is considered illegitimate. In this section we will look at what these concepts mean and how they intersect with those ideas previously discussed.

Let us start with malingering. This is a well-known and historically resilient concept but actual legal examples or clinical applications are scarce. There is, it seems, no one, clear definition of malingering, and though it frequents legal, medical and psychiatric spheres it fails to make a home in any of them.⁹⁰ In all, it is unstable and untested as a theoretical concept, either subsumed into other categories like fraud or else partially medicalised. However, malingering does carry with it a large amount of social weight, and examples are easily found in films, books and real-life. This has generated a pejorative set of meanings around the idea, which in turn negatively affect those tarred with its brush.

The basic concept is common knowledge: malingering is the act of pretending to be sick, or of injuring yourself, in order to gain in some way. Although associated

⁹⁰ Raine, A. 'Malingering and Criminal Behaviour as Psychopathology' in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, p. 103.

firmly with military service, it morphed during the 20th century and expanded, becoming more than just self-inflicted injuries and faked symptoms as ways of avoiding war.⁹¹ Now, it applies to anyone who declares themselves sick, or artificially induces illness in order to gain materially or by being able to give up responsibilities.

Central to the idea of malingering is 'secondary gain', which is that an individual must aim to benefit in some way from their deception. In a 21st century context, this will ordinarily come in the form of social security benefits, litigation payment or time off work. Emotional rewards are not normally included here, but the sympathy and good-will of others could be added to the overall package of benefits one hopes to achieve through their actions. Malingering stretches from phoning in sick when you are in fact planning to spend the day at the zoo to a calculated deception intended to bring you large rewards, for example pretending to be grossly injured following a workplace accident. Key to this idea is conscious intent: the person involved must be aware of the reasons behind their actions (even if this turns out to be rationalised in an overly-simplistic manner or is reliant on false premises). However, secondary gain is a 'highly speculative and empirically untested' concept, and finding medical or legal applications for malingering proves troublesome.⁹²

Clinically, it can be difficult to recognise individuals who are faking symptoms, and

⁹¹ Palmer, I. P. 'Malingering, shirking and self-inflicted injuries in the military' in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, pp. 42-53.

⁹² Rogers, R. and Neumann, C. S. 'Conceptual issues and explanatory models of malingering' in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, p. 74.

malingering is ‘a description of behaviour’, *not* a medical diagnosis.⁹³ Doctors are not trained or especially expected to identify them, and it has been suggested that some ‘maintain an undiscerning naïveté’ about the potential for patients to lie or deceive.⁹⁴ Malingerers pose a unique problem for doctors in that they invert completely what is expected of a patient. By ‘their very nature’ these individuals attempt to ‘evade any normal doctor-patient relationship’ and enter the surgery or hospital with very different priorities to most.⁹⁵ In any case, demarcating this phenomenon from actual disease is a process fraught with difficulty, and clinical skills are not always sufficient for this task. Even equipped with tools such as Symptom Validity Testing, attributing specific, motivated intent is speculative and malingering remains a ‘weak diagnosis of exclusion’.⁹⁶ Doctors are also not best placed ethically to identify malingerers, and if the levels of fraud reported by the health insurance industry are correct, they are not very successful at it either. This has been partially confirmed by studies which show doctors have difficulty detecting deception in a clinical setting.⁹⁷

Ultimately, the case has been put that in most instances it is more important to accept complaints and symptomatic patterns that you are uncertain of as a doctor

⁹³ That is to say, unlike factitious disorders (discussed below), malingering is not considered to be pathological and though doctors undoubtedly encounter it, they do not approach it as a medical issue; Boon, N. A., Colledge, N. R., Walker, B. R. and Hunter, J. A. *Davidson’s Principles and Practice of Medicine*, 20th edition, 2006, Churchill Livingstone, UK, p. 251.

⁹⁴ Cunnien, A. J. ‘Psychiatric and Medical Syndromes Associated with Deception’ in Rogers, R. (ed.) *Clinical Assessment of Malingering and Deception: Second Edition*, 1997, The Guildford Press, USA, p. 23.

⁹⁵ Bayliss, R. I. S. ‘The deceivers’ in *The British Medical Journal*, 1984, Vol. 288, No. 6417, p. 583.

⁹⁶ Pankratz, L. and Erickson, R. C. ‘Two views of malingering’ in *Clinical Neuropsychologist*, 1990, Vol. 4, Issue 4, p. 383.

⁹⁷ Jung, B. and Reidenberg, M. M. ‘Physicians being deceived’ in *Pain Medicine*, 2007, Vol. 8, No. 5, pp. 433-437.

than go down the opposite route.⁹⁸ This alternative road might lead to rejecting genuine distress because a cynical and suspicious environment has been allowed to develop.

Two distinct though related concepts complicate the clinical picture of malingering in psychiatry. The first of these are known as factitious disorders, a family of psychiatric conditions in which a patient fabricates illness, either through inducing symptoms or self-reporting problems they don't have in order to receive medical care in the shape of concern from their doctor, blood tests from the hospital and in extreme cases invasive surgery.⁹⁹ The aim here is not material gain, and this is what separates it from malingering. Instead, individuals hope to satisfy a psychological need, to allay some deep personal unease through becoming a patient. The lengths to which people will go to get their sick role legitimised are frequently extraordinary, and it is this lack of rational 'cost-benefit' analysis which further separates them from malingerers. The pertinent questions in these cases often becomes: at what point do we consider lying and deceit pathological and does it matter that the gains achieved are not material? In recent times the amount of clinical information available online has widened the opportunities for those with this condition.¹⁰⁰

The second set of illnesses often confused and conflated with malingering are known as somatic symptom disorders. Though comprising many parts, these largely arise when psychological distress and anxiety in a patient subconsciously transfers or 'converts' into physical symptoms. These manifestations can look and feel

⁹⁸ Robinson, W. P. 'The contemporary cultural context for deception and malingering in Britain' in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, p. 135.

⁹⁹ This condition or group of conditions is more famously and historically known as Munchausen's syndrome. For an overview, see: Folks, D. G. 'Munchausen's syndrome and other factitious disorders' in *Neurologic Clinics*, 1995, Vol. 13, No. 2, pp. 267-81.

¹⁰⁰ Cunningham, J.M. and Feldman, M. D. 'Munchausen by Internet: current perspectives and three new cases' in *Psychosomatics*, 2011, Vol. 52, pp. 185-189.

no different to the individual than if they were experiencing them in an orthodox manner. Unsurprisingly, somatic symptom disorders have a long and troubled history of confusing and upsetting both patients and doctors.¹⁰¹ What separates them from malingering is intent: these symptoms are not produced or reported with any desire to deceive, and often doctors have a better grasp of their production than the patient does. There is some common ground between malingering, factitious disorders and somatic symptom disorders, for example the responsibility placed on certain arbiters (normally medical staff) to ascertain both the level of conscious awareness that a patient has and their potential motivations.¹⁰² Teasing apart these separate but overlapping concepts is not an easy task.

Legally, malingering is a murky and ill-defined entity, and many doubt its existence as a distinct legal concept. Thus Jones argues that ‘malingering is occasionally central but often marginal, if not irrelevant, to the court’s decision making process’ and Sprince writes: ‘the law’s position on malingering is characterised by the absence of substantive and definitive features and by an indifference to any imperative to acquire them’.¹⁰³ This is largely because it is either subsumed under existing illegal activity like fraud and perjury or lives a life of its own within military and prison structures (where it has a long history).

In specific contexts it does appear to gain a little clarity and distinction: most notably in matters of compensation and welfare. There is evidence of patients faking

¹⁰¹ Hurwitz, T. A. ‘Somatization and Conversion Disorder’ in *The Canadian Journal of Psychiatry*, 2004, Vol. 49, No. 3, pp. 172-178.

¹⁰² For a thorough overview of the three topics discussed - malingering, factitious disorders and somatic symptom disorders - see: Bass, C. and Halligan, P. ‘Factitious disorders and malingering: challenges for clinical assessment and management’ in *The Lancet*, 2014, Vol. 383, No. 9926, pp. 1422-1432.

¹⁰³ Jones, M. A. ‘Laws, lies, and videotape: malingering as a legal phenomenon’ in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, pp. 209-219; Sprince, A. ‘Malingering and the law: a third way’ in Halligan, P. W. and Bass, C. (eds.) *Malingering and Illness Deception*, 2003, Oxford University Press, UK, p. 241.

or exaggerating symptoms in cases of post-traumatic stress disorder, brain injuries, whiplash and chronic pain amongst others.¹⁰⁴ However, here the definition of malingering becomes extremely context-dependent, and ambiguities remain, especially surrounding methods of detection. Exaggeration of non-specific symptoms for example can be extremely difficult to prove, and whether it warrants the use of problematic and intrusive methods such as surveillance and character assessment is undecided. Too much weight is put on conjecture to allow malingering to be considered a solid theoretical entity in this situation.

Compounding these problems is the dearth of data that has been collected on malingerers. We have only very rough figures for how many there might be under any given diagnosis, and what this translates into in terms of cost to the health care and insurance industries is equally unknown. First-person accounts are lacking for obvious reasons. Malingering is best characterised as a slippery concept that is not fit for purpose in the majority of circumstances that it might reasonably be applied in. Sharpe succinctly describes the difficulties faced by researchers as the following: ‘theoretically, malingering is distinguished from psychiatric illness by the absence of psychopathology, the identification of ‘secondary gain’, and a conscious intent to deceive in order to obtain the gain. However, psychopathology is hypothetical, secondary gain is non-specific, and the determination of the extent that intent is

¹⁰⁴ Rosen, G. M. and Taylor, S. ‘Pseudo-PTSD’ in *Journal of Anxiety Disorders*, 2007, Vol. 21, pp. 201-210; Greiffenstein, M. and Baker, J. ‘Miller was (mostly) right: head injury severity inversely related to simulation’ in *Legal and Criminological Psychology*, 2005, Vol. 11, pp. 131-145; Greve, K. W., Ord, J. S., Bianchini, K. J. and Curtis, K. L. ‘Prevalence of malingering in patients with chronic pain referred for psychologic evaluation in a medico-legal context’ in *Archives of Physical Medicine and Rehabilitation*, 2009, Vol. 90, Issue 7, pp. 1117-1126; a recent example of this kind of behaviour is the spate of food-poisoning cases brought by British tourists against continental resorts, vastly out of proportion to the other nationalities that holiday there.

conscious probably impossible'.¹⁰⁵ That is to say, each constituent conceptual part of malingering begins to look suspect under further examination.

This being true, malingering does cast a shadow over our cultural life, and it is here that perhaps it exists most vividly. Malingering is imbued with moral significance, and the osmosis of common tropes by both medical and non-medical figures contributes greatly to patients' understanding and experience of the term.

There are no shortage of cultural examples to choose from. Norman Mailer's debut novel *The Naked and the Dead* included a character who attempted to fake the symptoms of nervous shock to get removed from the front-line. *Seinfeld's* George Constanza pretended to be disabled so that he could access the executive bathroom. The traditional reading of *Hamlet* has the woebegone prince feign (rather than suffer from) madness in order to extract his revenge on Claudius. And sometimes real life provides examples that are stranger than fiction.

Consider the extraordinary case of Steven Jay Russell. Among the duplicity and many daring escapes that littered his criminal career, one particular scheme stands out as a masterclass in malingering. Through a combination of laxatives, starvation and convincing acting he was able to fake the symptoms of late stage AIDS and get himself removed from prison and placed in a hospice (where he subsequently engaged in further ingenious deception and faked his own death in order to escape).¹⁰⁶

Kuperman's content analysis on representations of malingering in works of fiction identified 'madness' and 'folly' as the two behavioural patterns most commonly used.¹⁰⁷ Whilst these are often employed as plot devices and as a basis for humor-

¹⁰⁵ Sharpe, M. 'Distinguishing malingering from psychiatric disorders' Halligan, P. W. and Bass, C. *Malingering and Illness Deception*, 2003, Oxford University Press, UK, p. 156.

¹⁰⁶ McVicker, S. *I Love You Phillip Morris*, 2003, Miramax Books, USA.

¹⁰⁷ Kuperman, V. 'Narratives of psychiatric malingering in works of fiction' in *The Journal of Medical Ethics; Medical Humanities*, 2006, Vol. 32, pp. 67-72.

ous passages, one consistency should be noted, that ‘in fiction, as in the clinic, malingerers often prefer mental disorders to somatic diseases’.¹⁰⁸ Because the majority of mental illnesses are symptomatic - that is, defined only by the symptoms as subjectively reported and recorded - it is a truism that faking such a condition is far easier than altering your body so that it falls in line with biological indicators of specific conditions. The same is true for contested illnesses, which are also largely symptomatic.

So, despite the ambiguity that dominates the theoretical debate around malingering, it would be foolish to dismiss this idea off hand. However defined, this is an issue which has been growing in importance over the last century and may continue to do so. There are some troubling trends which pay testament to this and defy simplistic explanations. Since the 1970s, more generous sickness benefits have generally become available across the majority of Western nations. Over the same period, the uptake of such benefits has increased dramatically and without signs of slowing, despite widespread improvements in general levels of public health, occupational safety, dietary information and interventionist medical care.¹⁰⁹ Partially this paradox can be explained by the explosion of ‘medically unexplained symptoms’ or ‘subjective health complaints’, which cover the majority of chronic, contested illnesses and whose patient populations often attempt to access sickness benefits of one kind or another.¹¹⁰ How are these patients affected by the medical, legal and cultural meanings of malingering?

For many individuals, especially sick people, the word ‘malingerer’ is heavily

¹⁰⁸ Ibid., p. 68.

¹⁰⁹ Haligan, P. W., Bass, C. and Oakley, D. A. 2003, p. 3.

¹¹⁰ Ford, C. V. ‘Somatization and fashionable diagnoses: illness as a way of life’ in *The Scandinavian Journal of Work and Environmental Health*, 1997, Vol. 23, Supp. 3, pp. 7-16; Binder, L. M. and Campbell, K. A. ‘Medically Unexplained Symptoms and Neuropsychological Assessment’ in *The Journal of Clinical and Experimental Neuropsychology*, 2004, Vol 26, No. 3, pp. 369-392.

loaded. It comes with a host of accusatory connotations which grate against the dominant positive narratives of selfhood present in modern society. In the wider scheme of things, to be a malingerer goes against the idea that everyone must contribute in some way, most often economically, to society, as best they can. Those who can but do not do this, or who find ways of circumventing this responsibility, are placed with scorn into a unsavoury category of people: ‘scroungers’ and ‘cheats’. Malingering fits nicely into many people’s view of society as constructed of those who work and deserve the rewards they receive and those who refuse to, riding instead on the coat-tails of *better* people, free-loading on an overgenerous state. On a personal level, being a malingerer makes you by definition a liar and a devious manipulator. People do not accommodate such views of themselves easily, and so it is no wonder that being regarded in this way often provokes a violent defensiveness.

For patients with chronic, contested illnesses, this is a particular concern because of the ‘subjective’ nature of their complaints. Having a purely symptomatic illness can generate the uncomfortable feeling that those around you and those professionally responsible for your well-being have ceased to trust the way that you represent yourself. There is definitely truth in this: focusing on fibromyalgia for instance, different research has shown that a significant percentage of doctors and a lower but still relevant number of specialists doubt the credibility of the disease, and many believe outright that those who claim to suffer from it are malingering.¹¹¹ What has also been highlighted, as suggested above, is the fairly straightforward way in which the clinical features of the illness could be feigned, and some re-

¹¹¹ Hayes, S. M. *et al* ‘Fibromyalgia and the therapeutic relationship: Where uncertainty meets attitude’ in *Pain Research and Management*, 2010, Vol. 15, No. 6, pp. 385-391; Album, D. and Westin, S. ‘Do diseases have a prestige hierarchy? A survey among physicians and medical students’ in *Social Sciences and Medicine*, 2008, Vol. 66, No. 1, pp. 182-188.

search points towards inconsistent reporting of symptoms.¹¹² More strongly suggested is that on some level an *exaggeration* occurs, facilitated perhaps by ‘an unconscious need to seek legitimisation of symptoms in the context of ‘disbelief’ by others’.¹¹³ As a result of this, sufferers of these illnesses often develop strategies for operating within this climate: a morgellons disease (a condition described further in Chapter II) organisation, for example, provides a cover letter to show to your physician whilst other groups emphasise different tactics that will make navigating the benefits system easier.¹¹⁴ The idea here is not to somehow cheat or deceive, but rather to recognise the often prejudicial circumstances that ill people find themselves in and to make the most of the tools available.

A concept that is sometimes brought into play when discussing these conditions is known as ‘compensation neurosis’. This is a term which is often used pejoratively to describe the apparent increase in symptom severity noted in those pursuing compensation which can abide or dissipate following a successful outcome. Some speculate on this basis that the rise of welfare opportunities for the ill has caused the growth in symptomatic conditions, arguing that ‘financial reward or compensation for self reported pain or suffering would seem to be more harmful than helpful’.¹¹⁵ Compensation neurosis is a more complex phenomenon than it first appears however: it is not simply a case of individuals overplaying their hand in or-

¹¹² Johnson-Greene, D., Brooks, L. and Ference, T. ‘Relationship between performance validity testing, disability status and somatic complaints in patients with fibromyalgia’ in *Clinical Neuropsychology*, 2013, Vol. 27, No. 1, pp. 148-158.

¹¹³ Harth, M. and Nielson, W. R. ‘Fibromyalgia and disability adjudication: No simple solutions to a complex problem’ in *Pain Research and Management*, 2014, Vol. 19, No. 6, p. 296.

¹¹⁴ For example see <http://fibroaction.org/Pages/Benefits-and-Fibro.aspx> archived on 19/07/17 at <http://www.webcitation.org/6s5Ef6f3i> for fibromyalgia; <http://www.actionforme.org.uk/get-informed/welfare-benefits> archived on 19/07/17 at <http://www.webcitation.org/6s5ElJxZ6> for chronic fatigue.

¹¹⁵ Bellamy, R. ‘Compensation Neurosis: Financial Reward for Illness as Nocebo’ in *Clinical Orthopaedics and Related Research*, 1997, No. 336, pp. 94-106.

der to squeeze money out of the system. As Hall and Hall have argued, finding yourself in a compensatory struggle presents a unique set of stressors, only one of which is potential financial reward.¹¹⁶ What may well be more pertinent is the pressure exerted by lawyers, family and friends to experience your condition in a certain way, or the effect of continually retelling and reasserting your subjective symptoms in a climate of doubt. It is these processes which can in some people (different groups of individuals have been shown to be more or less susceptible) generate the unconscious expansion of symptoms.

As we shall see in Chapter IV, there is some truth to this idea, though it is a murky and complex process to unpick. What I observed through my conversations with fibromyalgia patients did not appear to be a straightforward exaggeration of symptoms in order to gain some kind of reward. Rather, it was two processes occurring simultaneously. The first is the tailoring of their disease, or how they reported their disease, to the rigid requirements of different contexts. Even when it was not the case, they tried to present their condition as much as possible in ways which accorded with institutional and societal expectations, most having learnt the hard way that telling the truth (as they saw and felt it) about their symptoms was not always fruitful. The second process is the hard to grasp subconscious effects of living with a symptomatic profile not understood or valued by the social matrix of your life, i.e. the struggle to live well and trust your body whilst lacking empathy and validation from others around you. Though the effects of this are difficult to determine, I would say it clearly has the potential to play a big role in the way that symptoms are conceptualised by patients, and perhaps in some cases does lead to a defensive ‘hardening’ of the way they interpret their distress.

Subjective health complaint patients do come under legal scrutiny for compensation neurosis, but it is worth noting that in many instances the hope of financial

¹¹⁶ Hall, R. C. W. and Hall, R. C. W. ‘Compensation Neurosis: A Too Quickly Forgotten Concept?’ in *The Journal of the American Academy of Psychiatry and the Law*, 2012, Vol. 40, pp. 390-398.

compensation from the very beginning is understood to be slight, and some do not engage in the process at all. There also seems to be little evidence of patients recovering or part recovering after receiving welfare approval, though it is argued that in the case of chronic conditions these payments incentivise patients to remain ill rather than get better and lose entitlement. In many cases, people remain ill, housebound and unable to work regardless of the level of assistance they receive. What is interesting though is the idea that constant narrative reinforcement of symptoms can solidify and worsen them. For many patients however, as I will talk about in Chapter IV, this persistent retelling and negotiation of their sickness identity appears to generate self-doubt and foster concealment strategies rather than any hardening of symptom narratives. Potentially shorter-term, more one-off compensatory situations, such as those regarding whiplash following an accident for example, seem more likely candidates for examining this concept thoroughly. To bring this conversation full-circle, it seems like we have covered a lot of ground without saying much which is conclusive. And yet the way that patients feel about their conditions *is* intimately related to these concepts. There seems to be one extra component which is missing: the incredibly strong and emotive link that people draw between a condition being ‘psychological’ or ‘psychosomatic’ and it being controllable. Indeed, patients themselves have been shown to view psychosomatic illness and malingering as synonymous, regardless of attitudes within medicine and psychiatry.¹¹⁷ It is clear that the most important aspect of malingering for those with contested illnesses is *agency*. Agency brings with it that which is dreaded: responsibility. As Hacking states:

¹¹⁷ Wessely, S. and Showalter, E. ‘Chronic fatigue syndrome: a true illness or a social and political issue?’ in Williams, G. (ed.) *Horizons in Medicine*, 1999, Vol 10, Royal College of Physicians, UK, pp. 501-516.

‘Responsibility is the crux. We have a profoundly moral attitude to disease. If something is a real disease, you are not responsible for it’.¹¹⁸

And thus, for some people with contested illnesses, the mere suggestion that *any* part of what they suffer from might be psychological in origin can entail the subsequent conclusion that the person making that diagnosis is accusing them of being in control of their symptoms. That is, since psychosomatic conditions are not ‘real’ in the eyes of sufferers - organic, biomedical conditions being the only ones which ‘count’ - they are therefore the fault of the individual who contracts them or displays their symptoms. Kirmayer describes the diagnosis of a psychosomatic condition as transforming the ‘real into the imaginary, the innocent into the culpable’.¹¹⁹ As we shall see in Chapter IV, not all patients reject this label as strongly as is often suggested, some fully incorporating a psychological element to their problems, but what does remain constant is the desire to be absolved of blame. Showalter writes about CFS patient ‘culture’ which contributes to prioritising biological explanations:

‘Patients with chronic fatigue live in a culture that still looks down on psychogenic illness, that does not recognise or respect its reality. The self-esteem of the patient depends on having the physiological nature of the disease accepted: the culture forces people to deny the psychological, circumstantial, or emotional sources of their symptoms and to insist that they must be biological and beyond their control in order for them to view themselves as legitimately ill’¹²⁰

¹¹⁸ Hacking, I. *Mad Travelers: Reflections on the Reality of Transient Mental Illnesses*, 2002, Harvard University Press, USA, p. 11.

¹¹⁹ Kirmayer, L. J. ‘Mind and Body as Metaphors: Hidden Values in Biomedicine’ in Gordon, D. and Lock, M. (eds.) *Biomedicine Examined*, 1988, Kluwer Academic Publishers, The Netherlands, p. 65.

¹²⁰ Showalter, E. *Hystories: Hysteria, Gender and Culture*, 1997, Pan Books Limited, UK.

The last two words used above are those that patients most often repeat: their condition is not regarded as legitimate and therefore they are not believed to be legitimately ill. Legitimacy here also means that an ill person *has the right* to feel the way they do, to be excused from working, to receive welfare payments, to expect sympathy, etc. because their condition is 'real'. As a reaction to this, what has been observed across many contested illnesses is the formation of alternative models of legitimation, which posit versions of aetiology, diagnosis, prognosis and treatment that are removed from the mainstream medical view.¹²¹ These explanations extend to covering the difficulties that their conditions present and 'helps sufferers deal with conflicting medical and cultural representations of their illnesses by explaining why contested illnesses are so hard to diagnose and treat'.¹²²

Closely related to this is the idea of validity: that if a disease is not legitimate then therefore the symptoms and associated distress of the ill person becomes invalid. This is viewed by many patients as a deeply painful denial of their personal experience, especially as it can come not only from medical professionals but from those closest to them - friends, children, partners. A recurring theme among patients with fibromyalgia (expanded in Chapter IV) is that although others 'try to understand', nobody except fellow patients really has access to their symptomatic world. A lot of people within the community point to explanatory strategies such as

¹²¹ Swoboda, D. A. 'The social construction of contested illness legitimacy: a grounded theory analysis' in *Qualitative Research in Psychology*, 2006, Vol. 3, pp. 233-251.

¹²² *Ibid.*, p. 245.

‘spoon theory’ as a way of conveying to those without the condition what it is like to suffer from it.¹²³

This does not, however, alter the fact that for many patients, the way that their body makes them feel is sufficiently removed from how others perceive that experience as to create severe psychological tension. Despite the attempts of the patient community to pursue alternative legitimatising models and even in possession of fortitude and self-belief, patients still remain engaged in a struggle to validate their own embodied existence.

This issue is, I believe, best explained as a form of conceptual distance, whereby the phenomenology of disease for those with contested illnesses (and others) is mismatched with prevailing notions of what disease *should* be, creating a gap between people’s expectations and a patient’s experience. To begin to look more in-depth at this problem, we must first examine the pervasive but fuzzy historical and philosophical idea, ‘biomedicine’.

It is this loose system of thought or, rather, way of seeing and encountering disease, which more than any other set of ideas guides us, both as specialists and non-specialists, when it comes to sickness. Though it has brought us many benefits, there are plenty of instances where the biomedical worldview is simply unable to adequately account for phenomena it is expected to assimilate. Contested illnesses being one such group, in which disease experiences are rendered almost entirely incomprehensible by biomedical attempts to classify and explain. Such is the ubiquity of its basic tenets that they have come to represent the common-sense under-

¹²³ ‘Spoon theory’ is an analogy that describes the way conducting seemingly mundane and everyday tasks can drain the energy of someone with a chronic illness. People with chronic illnesses start each morning with a predetermined number of ‘spoons’, and use them up throughout the day on whatever activities they attempt, to the point where if all spoons are depleted then they have no option but to rest. This is contrasted to able-bodied, healthy people who have a ‘never-ending’ supply of spoons and do not have to adjust their actions on the basis of how many they have left. This explanatory tool is not used exclusively by people with contested illnesses, but also by individuals with disabilities and other chronic diseases.

pinnings of categories like ‘disease’, and those conditions which does not appear to fit have become strange category errors, unable to ascend to full disease status.¹²⁴ The damage done by this incompatibility will be explained at length in Chapter IV. But first, what exactly do we mean when we talk of ‘biomedicine’?

Biomedicine

In 1936, Henry Sigerist wrote that ‘medicine is not a branch of science and it never will be’.¹²⁵ He was engaged in a dispute with George Sarton about the nature of their disciplines’ relationship (history of medicine and history of science respectively) at the time, but what is relevant is the way in which he regarded medicine as an intrinsically *social* enterprise. In the years that have passed since, this assertion has not lost relevance. If anything, the need to emphasise those aspects of medicine which are not scientific, especially in relation to the topic at hand here, is greater than in Sigerist’s era. This is because of the dominance of the ‘scientific’ branch of medical practice, which has expanded vastly in scope and power following the Second World War. In this section, I will outline what are regarded as the core features of biomedicine and discuss some common objections and critiques, mostly drawn from sociology. I will then look at the implications of the biomedical model for chronic, contested illnesses and bring greater clarity to the notion that this can be framed as a philosophical problem as well as a sociological one.

Though it is possible to trace the beginnings of biomedicine, philosophically, far back into the nineteenth century, through the work of Koch, Pasteur and Bichat

¹²⁴ Though it must be said that contested illnesses, for a variety of reasons, have rarely been fully accepted as completely legitimate disease entities, at least from the 20th century onwards.

¹²⁵ Sigerist, H. ‘History of Medicine and the History of Science: An Open Letter to George Sarton, Editor of *Isis*’ in *The Bulletin of the History of Medicine* 1936, Vol. 4, pp. 1-13.

(and perhaps even further to Descartes), it is not an unreasonable assertion to make that the modern features of this phenomenon only began to solidify and permeate in the post-war period, where biological science and clinical practice converged at the start of the antibiotic age.¹²⁶ This is because, with the new focus on identifying and eliminating foreign agents as a primary method of fighting disease came a new set of assumptions about what medicine *is* and *does*. It is here that a closer, more intimate relationship developed between the laboratory and the hospital, training began to contain an explicit, scientific core and a series of seemingly incredible victories over long-standing scourges (tuberculosis and syphilis for example) shaped the narrative of interventionist, miraculous medicine.¹²⁷

Thus it was that a way of seeing the medical world which had long been intellectualised - the development of the dichotomised body as object and subject, the preference for measurement over speech - spread gradually across the medical and then social worlds of the west, normalised and perpetuated through schools and universities.¹²⁸ In time biomedicine has become more and more demarcated from other models of understanding health, disease and medical treatment, and is the dominant viewpoint from which to understand disease, both by medical personnel (sometimes to an incredible level of specificity) and by lay populations, albeit in a much more intangible, fluid manner. But what are its constituent parts?

The core tenets of Biomedicine

¹²⁶ Keating, P. and Cambrosio, A. *Biomedical Platforms: Realigning the Normal and the Pathological in Late-Twentieth-Century Medicine*, The MIT Press, USA, 2003.

¹²⁷ Quirke, V. and Gaudillière, J. 'The Era of Biomedicine: Science, Medicine, and Public Health in Britain and France after the Second World War' in *Medical History*, 2008, Vol. 52, pp. 442-443.

¹²⁸ Mol, A. and Law, J. 'Embodied action, enacted bodies' in Burri, R. V. and Dumit, J. (eds.) *Biomedicine as Culture: Instrumental Practices, Technoscientific Knowledge and New Modes of Life*, 2007, Routledge, UK, pp. 88-89.

Sarah Nettleton identifies five core tenets, and these serve as a good starting point as they encompass the major trends without necessitating too much deviation or lengthy exposition.¹²⁹ They are as follows:

- 1) Mind-body dualism: the mind and the body are treated separately; disease relates to the body;
- 2) Mechanical metaphor: the body is best understood as a complicated machine with independent parts and systems that can be repaired individually;
- 3) Technological imperative: technological interventions are prioritised; there is a bias towards curing rather than caring;
- 4) Reductionism: health and illness are explained in strictly biological terms; sociological, environmental or psychological factors are downplayed or disregarded unless no organic cause can be identified;
- 5) Doctrine of specific aetiology: disease entities are solely responsible for disease.

Mind-body dualism in this context refers to the dichotomisation between what are regarded as ‘subjective’, mental complaints and ‘objective’, physical ailments, with the latter prioritised as more legitimate. The physical and mental domains of health as schematised here are separated to a large extent in training, research and clinical practice in western medicine. Distinct institutional and professional divisions exist, and generally speaking ‘physical’ medicine is held in higher esteem. This split no doubt contributes to the lack of parity that exists between mental and physical disorders, and the result is often that conditions that do not produce consistent or convincing biomedical markers are regarded as suspicious, irrelevant or overly time-consuming by practitioners.¹³⁰

¹²⁹ Nettleton, S. *The Sociology of Health and Illness*, 2006, Polity Press, UK, p. 2.

¹³⁰ Crowley-Matoka, M. *et al* ‘Problems of Quality and Equity in Pain Management: Exploring the role of Biomedical Culture’ in *Pain Medicine*, 2009, Vol. 10, No. 7 p. 1314.

The second factor that Nettleton identifies is the employment of a mechanical metaphor to explain how the human body works and by extension how to fix it when things go wrong. Abstract representations of anatomy and physiology include numerous references to the body-as-machine, and medical textbooks regularly and explicitly make this connection. This is related to the third and fourth factors: the body is essentially reduced to a collection of parts and systems that can be repaired through interventions aimed at specific problems. Viewed this way, the patient is a complex construction, with various interdependent parts, most of which can to some extent be isolated and worked on individually. The aim of medicine here is always to cure, to restore the body as close as possible to the state it was in before the problem arose. The outcome of this mechanistic, reductionist approach is that the clinical focus turns to biological rather than psychological or social factors to explain and encounter disease. Health becomes a largely physiochemical concept.¹³¹ Biomedicine ‘exemplifies materialism...‘real’ illness corresponds to the degree to which physical traces show up in the body...health and illness are defined in terms of materialist indicators’.¹³²

The doctrine of specific aetiology, identified by Nettleton as the final core feature of biomedicine, states that all diseases are caused by identifiable factors, preferably singular ones that can be observed by technical means. This concept has a long history, and though it is widely accepted that most diseases are multifactorial and that the presence of certain bacteria may be benign in some and pathological in others, this idea still exerts influence in both medical and lay contexts.¹³³ In many

¹³¹ Helman, C. G. ‘Psyche, soma, and society: the social construction of psychosomatic disorders’ in Gordon, D. and Lock, M. (eds.) *Biomedicine Examined*, 1988, Kluwer Academic Publishers, The Netherlands, p. 95.

¹³² Gordon, D. ‘Tenacious assumptions in modern medicine’ in Gordon, D. and Lock, M. (eds.) *Biomedicine Examined*, 1988, Kluwer Academic Publishers, The Netherlands, p. 24.

¹³³ Deep, P. ‘Biological and Biopsychosocial Models of Health and Disease in Dentistry’ in *The Journal of the Canadian Dental Association*, 1999, Vol. 65, pp. 496-497.

cases, where diseases are located around one body part or system, or else result from one virus or bacteria, and other contributing elements are deemed to be of minimal importance or disregarded altogether. As Lawler writes: ‘such a viewpoint leaves little space for other aspects of lived experience, such as feelings and emotions, except to the extent that these things can be understood as biologically determined processes’.¹³⁴

This approach to healthcare has certainly had its benefits. It is indisputable that advances in microbiology (and related fields) and their widespread application has saved a magnitude of lives and vastly increased the power of medicine to react and to heal. A large number of illnesses fit neatly into this understanding of health and sickness, and acute care is more effective than it has been in the history of mankind.¹³⁵ Rising life expectancy and steadily increasing clinical outcomes over the latter half of the 20th century are due, in some part at least, to the strengths of the biomedical model in combating disease.

However, it is arguable that other factors – improvements in personal and professional hygiene, public health campaigns, sanitation, education, housing, employment, air quality, diet – have all had a greater effect on the health of western populations than interventionist medicine.¹³⁶ Biomedicine, in failing to recognise or appropriately regard the socio-environmental context in which disease forms, is inadequate and unable to achieve its aims.¹³⁷ There is also the problem that a biomedical viewpoint assumes that its methods produce epistemic authority - that all

¹³⁴ Lawler, J. *Behind the Screens: Nursing, Somology and the Problem of the Body*, 1991, Churchill Livingstone, Australia, p. 2.

¹³⁵ Wade, D. T. and Halligan, P. W. ‘Do Biomedical Models of Illness Make For Good Healthcare Systems?’ in *The British Medical Journal*, 2004, Vol. 329, No. 7479, p. 1398.

¹³⁶ Nettleton, S. 2006.

¹³⁷ Broadly speaking, these aims are: restoring to health all those who are ill through specific, targeted treatment and identifying singular causes or physiochemical aetiologies for all conditions.

validity surrounding a disease must be drawn from microbiology or histology or physiology or parasitology (or whatever). This not only ignores non-biological factors as discussed above but also assumes that medical knowledge production is ‘objective’ and without roots in a specific social context, despite much work which has demonstrated otherwise.¹³⁸

It is notable that the most strident criticisms of biomedicine have come from sociologists. Their work, as discussed in this chapter, has enabled us to give meaning to health and sickness beyond that which is provided by medical science, and equipped us with tools to challenge the assumptions on which we base our health care system. This has provided some support for movements within medicine to establish a broader base for understanding illness, such as the biopsychosocial model, first proposed in the 1970s and often referred to if ‘apparently little applied.’¹³⁹

What is lacking however is any concerted effort to respond to biomedicine philosophically. Looking at how the body is understood by practitioners is vital because it determines the way in which health and illness come to be defined within disciplines and as a consequence points towards what is perceived as the best medical response to a situation.¹⁴⁰ It is also important to recognise how individuals and communities outside of medical practice perceive and experience health and ill-

¹³⁸ For two landmark case studies in the social production of knowledge, see: Fleck, L. *Genesis and Development of a Scientific Fact*, 1981 (originally published 1935), University of Chicago Press, USA and Latour, B. and Woolgar, S. *Laboratory Life: The Construction of Scientific Facts*, 1986, Princeton University Press, USA.

¹³⁹ Engel, G. L. ‘The need for a new medical model: a challenge for biomedicine’ in *Science*, 1977, Vol. 196, No. 4286, pp. 129-136; Johnson, S. B. ‘Medicine’s paradigm shift: An opportunity for psychology’ in *The American Psychological Association*, 2012, Vol. 43, No. 8, p. 5.

¹⁴⁰ Brown, C. and Seddon, J. ‘The social body and the biomechanical body: can they co-exist in nurse education?’ in *The Journal of Advanced Medicine*, 1996, Vol. 23, pp. 651-656.

ness as well, and the effect that this has on the sick. I have no doubts that this is as much a philosophical problem as it is a sociological one.

This is because biomedicine is a way of seeing disease, of seeing the body and of seeing bodies. The biomedical body is universal, consistent and constant; its ways of signalling distress can be quantified in numerical form; it can be fixed, it can be cured. Corporal regionalism reigns in the clinic. Diseases are malfunctions, external not always (though often) in the necessary sense of having come from outside, but rather in the sense that they are always *external to the norm*. A biomedical body should hold no surprises.

This model seeps into the popular imagination and informs the way that non-medically trained individuals encounter illness. To them, disease is visible, ill people *look ill* – they limp, they're pale, their hair falls out, they bleed. Diseases have scientific names because diseases are scientific entities. Disease is always located: you're ill because of this organ or that virus or because of some imbalance in your blood; you are never simply ill. Disease is something to be fought against and triumphed over or it is something to be defeated by; patients get better or they get worse; they do not fluctuate day by day.

This is not to say that this view is malevolent, but rather to state that there are many experiences of sickness which fall outside of these parameters. The patients involved, unsure of their own ideas about their body, conflicted as they are between what they have absorbed and what only they know, cannot find a home for their sensory life in the meanings, explanations and narratives offered by the biomedical model. They are lost, and turn to each other to share the burden of being misunderstood. In Chapter IV, through the words of patients we shall see the reach of the biomedical mindset, extending as it does far beyond the doctors' surgery and into family homes and offices, newspaper articles and online forums.

Concluding remarks

In the preceding pages we have covered in some detail the different concepts that seem most salient when it comes to discussing the philosophical context that informs the experience of those with chronic, contested illnesses. What we are left with now, as I try to bring these different conversations into some sort of coherence, is a vocabulary with which to understand real life experiences, and a set of questions that philosophical work in this area might try and answer. ‘Chronic’ diseases seem an unstable category but one which is useable enough so as not to be disregarded. ‘Contested’ illnesses, as I understand them, can be demarcated fairly successfully, though this is where the interesting analysis begins rather than ends. Both of these combined - as they almost always are - leaves us a sticky, viscous conceptual group, but one which promises to be extremely demonstrative of the problems surrounding philosophy of disease. ‘Malingering’ is brought in and partially dismissed for its conceptual viscosity, but retained as an item of utility due to its metaphorical power. It is important because of what it means to those affected and how it fits into larger societal narratives of justice and fairness. ‘Validity’ and ‘legitimacy’ are exposed as painful but essential components of the contested illness experience, and their own make-up is examined. The subterranean system which underpins all this, ‘biomedicine’, has been shown to have several key features and a distinguishable core which informs the way not only large areas of medicine operate but also how people in general view health and illness. In the next chapter we will look at how philosophers have written about disease, and what may appear the most remarkable about their work is the lack of thought devoted to the ideas presented above.

Chapter II - Definitions of Disease

In 1992, Arthur Caplan published a famous paper in *Theoretical Medicine and Bioethics* entitled ‘Does the philosophy of medicine exist?’.¹⁴¹ Within it he detailed various necessary features of a ‘field’ and concluded, broadly to his own disappointment, that philosophy of medicine did not satisfy those conditions. Therefore, it should not be yet considered a discipline in its own right and did not as such ‘exist’. His demarcation criteria were that a field must be integrated into cognate areas of study; it should have a distinct and wrangled-over canon of literature; and that there ought to be present some key puzzles or vital questions which form the centrepieces of the main debates. Philosophy of medicine, in his view, failed to make the grade in any of these three categories.¹⁴²

It is the first and last of Caplan’s criteria with which I am most interested here. He argued that philosophy of medicine is too removed from practice, and that philosophers do not do enough to place themselves as loud, useful voices in relation to medicine. It is this baton I would like to raise here. I broadly agree with his suggestion that philosophy of medicine is too insular and inward-looking, and that its proponents have not done enough to make themselves relevant.

Then there is the question of central problems. Caplan conceded that the debate surrounding ‘health’ and ‘disease’ comes closest to passing his test, but argues that these do not constitute enough to ‘transform a mixed set of ruminations into an

¹⁴¹ Caplan, A. ‘Does the philosophy of medicine exist?’ in *Theoretical Medicine and Bioethics*, 1992, Vol. 13, No. 1, pp. 67-77.

¹⁴² His overall thrust is fairly irrelevant to this work. I agree broadly with Stempsey’s retrospective and roughly inclusive view: Stempsey, W. E. ‘Philosophy of Medicine is What Philosophers of Medicine Do’ in *Perspectives in Biology and Medicine*, 2008, Vol. 51, No. 3, pp. 379-391. As such, the strength or weakness of Caplan’s position is not under discussion here, and I do not wish my use of his paper to be taken as a tacit endorsement of his views. I am using his work here as a springboard for discussion, not as an item for analysis itself.

actual field'.¹⁴³ In the years since his paper these concepts have been hashed out to a greater extent, perhaps even enough to contribute decisively to bonafide field-hood, but that is not what I am concerned with. What I would like to focus on in this chapter is philosophical attempts to define disease, the underlying motivations for such efforts and the extent to which these could be considered a success.

This is because I agree with Caplan, insofar as the definition of disease is a problem which is and has been central to the philosophy of medicine.¹⁴⁴ Its importance would seem to be based in part on the benefits of clear demarcation criteria. For a start, distinguishing between health and disease appears a prerequisite for the just distribution of limited resources within any healthcare infrastructure. The allocation of benefits, material, medical or social, seems to rely on being able to tell disease from non-disease. There are as well a large range of specific dividing lines which come to mind, such as the distinction between treatment and enhancement - whether we should then treat body dysmorphic disorder with cosmetic surgery for example - or indeed demarcating between treatment and amputation, which is often sought by those with body identity integrity disorder. Both of these could, in theory, benefit from greater clarity surrounding 'disease' and its hypothetical opposite 'non-disease'¹⁴⁵. The special interest here of course, contested illnesses, would seem to gain greatly from proper categorisation, as the uncertainty that exists at present bleeds credibility from patient's experience.¹⁴⁶ In any case, the examples

¹⁴³ Caplan, A., 1992, p. 73.

¹⁴⁴ As do Nordenfelt, L. 2013, p. 23 and Lemoine, M. 'Defining disease beyond conceptual analysis: an analysis of conceptual analysis in philosophy of medicine' in *Theoretical Medicine and Bioethics*, 2013, Vol. 34, No. 4, pp. 309-25.

¹⁴⁵ I make a distinction here between 'disease' and 'non-disease' not only because defining 'health', which most would take instinctively to be the opposite, has its own troubled definition history, but also because all that is not disease *is* 'non-disease', whereas plenty which is not disease is also not health.

¹⁴⁶ Though it remains to be seen what exactly would happen should their situations be judged or assigned to not be 'disease'.

touched upon here just a few of the topics which could be plausibly profit from a thorough and sophisticated elucidation of the term ‘disease’.

So yes, it would appear that answering, or attempting to answer, the question ‘what is disease?’ serves a useful purpose. However, in this chapter I will argue the opposite. Attempting to define disease in a universal, closed sense, is a futile exercise.

What’s more, it is one which gestates further futile exercises, in the form of a prolonged theoretical tussle from which no winner is ever likely to emerge. My argument is that philosophers who attempt a universal definition of disease, one which is able to sharply demarcate disease, are caught in an impossible bind. Maël Lemoine blames the procedural restraints of conceptual analysis for this, and I will explore his position. But I will also posit that there is another factor which makes their attempts unlikely to be fruitful.

I will show that given their aims, they either intend their theories to be descriptive or normative. In the case of the former, it is highly improbable, given the desire to generate a set of stipulations which includes all which is disease and excludes all which is not, that they will be successful. This is due to the sheer diversity of entities that might be considered ‘disease’ and some pressing but unconsidered epistemic issues. The creation of such a schema rests upon a necessary essentialism about disease which does not come close to enjoying adequate empirical support. I call this the vast magnitude argument, and I believe it applies even if you try and restrict disease entities to something that appears fairly self-contained (say, ‘medical’ usage) as well as to broader normativist theories of disease. For the latter, the normative angle, it is simply that their conceptualisations carry little weight and make no strong claims as to why we should respect their authority. I call this the justification gap argument. This argument has two strands: a theoretical deficiency which I will compare with bio-ethics and a practical element, which is that the words spoken in philosophy of medicine fail to echo anywhere else.

Furthermore, I will argue that theorists following this approach have a nefarious

influence on the discipline as a whole. Most notably, the focus on all-encompassing theories of disease steers problem selection away from practice and into the arms of pedantry. To quote Caplan again, recent work on disease definition has done little to challenge the idea that ‘the philosophy of medicine looks from afar like an intellectual island’ with no ‘connections to other parts of the intellectual map’.¹⁴⁷ Using Illari and Russo’s taxonomy of counterexamples, I will discuss how this problem might be approached and how plausible new directions in philosophy of disease would seem, utilising one promising section of the literature, phenomenology.

Before I do this, though, it would be worth outlining the field, questioning the key assumptions and aims of the philosophers, detailing some of the more influential positions that have been taken, and focusing on a few of the ways that people have approached the big questions surrounding disease: what is it and how should it be defined? I will make this section brief as there already exists voluminous literature on the topic and what is more pertinent here is how we move past the current strictures of debate.

Why define disease?

What is the purpose of achieving a succinct and self-contained definition of disease? As with any ‘defining of terms’ discourse, the possible outcomes are varied. Practical concerns, for example. Surely there is a straightforward, almost bureaucratic function to defining disease? After all, with the large amounts of public and private money spent on health-care, there must be an incentive to be able to adequately draw a line between who or what deserves resources. A strong, formulaic definition that could be referred to or imbued in practice would seem to serve a useful role. Certainly there are no shortage of controversial cases that would ap-

¹⁴⁷ Caplan, A. 1992, p. 72.

parently benefit from some appeal to a higher adjudicator, especially in state-funded and distributed healthcare.

Armed with such a definition, perhaps we could make progress on, for example, deciding whether people who eat fatty foods and exercise little become *sufferers* of obesity and therefore deserve access to relatively expensive surgical procedures. Or, to give another example, whether body dysmorphia qualifies as a disease and therefore should be treated (with cosmetic surgery for instance).¹⁴⁸ Indeed, politically, a strong and reductive disease definition could be wielded against medicalisation, over-diagnosis and fears of boundary creep.

Along with distributing concrete resources, a complete definition of disease would allow us to resolve some of the more fluid issues surrounding distribution, such as the allocation of sick roles, sympathy and the validation of an individual's embodied experience. These contentious and often painful battles to grab and hold on to legitimacy again could profit from reference to a higher, codified arbiter. Something like a gold standard in demarcation might play this role and be held up by those on the blurry edge of disease like a certificate, a qualification that entitles them to be sick.

Diagnostically, one of the merits of possessing a clean, useable definition is that it would enable health care professionals to make better decisions in the clinic. This is tied into concerns about medicalisation and over-diagnosis, in that a less vague disease concept is one which will simultaneously reduce false positives (especially with mental and behavioural conditions) and diminish the power of special interests to bend definitions to their advantage (pharmaceutical companies seem the obvious target but equally patient groups and insurance companies might fit this description).

¹⁴⁸ For an extended and fascinating discussion of these sorts of questions, see Elliott, C. *Better Than Well: American Medicine Meets The American Dream*, 2004, W. W. Norton and Company, USA.

It might even be conceived that a slight codification of demarcation criteria could be achieved whilst retaining some of the plurality of the current, organic, case-by-case, institution-by-institution system. That is to say, we could move towards having a regular set of demarcation criteria to be used economically in terms of resource allocation, whilst generating a different set for clinical situations and so on, which would still reduce greatly the number of stipulations for disease status in use. Essentially, this would represent a scaling down and centralising of the current situation, though some form of arbiter would still be required.

Finally, to return to the aims of philosophers, there is a conceptual mapping aspect to all of this. Put simply, disease exists in variant forms throughout institutions, cultures, individuals and time. It is real in the sense that people believe in its reality. Indeed, despite the high variance with which it is found over a great multitude of different contexts, its core 'reality' is for the most part undiminished. And so there is a solid and understandable drive to describe and explain this phenomenon conceptually, and integrate it into a nexus of related concepts, as is the case in other parts of philosophy for other entities. Whether this pursuit is a directly fruitful endeavour is not always the point; sometimes it is enough that the ideas were wrestled with and that the picture became slightly more in focus. Often the true yield of such work is initially obscure, and sometimes conceptual debates have surprising and pleasant outcomes far from the theoretical realm.

I am not convinced by the above arguments, at least in the sense that I think they rely on things that will not come to pass or that they have unintended and deleterious consequences, and my objections will be clarified and expanded at the end of this chapter. I have included these potential motivations for attempting the task here so that we can better analyse the success of various responses on their own terms.

Is this, then, what philosophers are trying to achieve? Are they hoping to define

disease in order to solve or advance some of the problems that I have outlined above?

Maël Lemoine looked in detail at three important writers on this topic - Christopher Boorse, Lennart Nordenfelt and Jerome Wakefield - and discussed the motivations that drive philosophers of medicine to attack this problem.¹⁴⁹ Though he found that each had a closely related but distinct ‘major goal’, which tended toward the broad and vague, he concluded that alongside this came common concerns similar to those I have raised.¹⁵⁰ These relate directly to the sort of advantageous consequences they perceive their definitions to have, for example eliminating false positives in diagnosis and resolving disputed or borderline cases. They also retain a strong link to the things generally considered to be ‘disease’, at least insofar as they represent a considerably large set of cases that must be satisfactorily assimilated for a definition to be considered successful. Finally, it would appear to be the case that some level of conceptual coherence is a worthwhile goal in its own right for these thinkers, and that work which is able to reconcile the different notions of ‘disease’, ‘health’, ‘mental illness’, ‘injury’ etc. which are currently present in the literature is deserving of attention.

It seems evident, therefore, that philosophers see themselves as having clear motivations for doing this kind of work, and that they anticipate benefits emerging from their attempts. Before I go into detail as to why I take a contrary view, it will be useful to describe the main positions that individuals take in this field.

Outline of the field

¹⁴⁹ Lemoine, M. 2013.

¹⁵⁰ Boorse aimed to define health and disease within somatic medicine, Nordenfelt wanted a definition of health in general and Wakefield limited himself to mental disorders. Lemoine notes that despite these apparently diverse goals, these three thinkers are able and willing to argue with each other as if their work was directly comparable. Certainly, by them and others, it has been treated as such.

Within the definition of disease debate (and discussion of health more widely), there have over the last thirty years emerged two loose groupings of theorists, shoe-horned into what philosophers love to call a ‘false dichotomy’.¹⁵¹ It is known as such due largely to the coherence and consistency of one thinker, Christopher Boorse, in the light of whom disparate opponents begin to seem united.

His ideas have formed the basis of the naturalist tradition, which positions disease as a series of entities which can be uncovered in a ‘value-free’ manner.¹⁵² In essence, naturalists argue that disease (along with health) is a concept which exists in the real world and can be described without evaluative elements needing to get involved. Specifically, the usual arguments employed are that disease is revealed in a body by a statistical abnormality, measured scientifically, which indicates that natural function (usually framed in evolutionary terms) has been impaired. Bodies consist of systems which have specific life-maintaining goals, and a departure from the normal functioning of these systems (which is not harmless or beneficial) amounts to a disease state. Conscious of some of the basic problems of normality, these statistical deviations are only considered significant if they are anomalous for the type (age, sex, ethnicity etc.) of person that experiences them. So, a young, ethnically Chinese woman who is lactose intolerant and gets drunk quickly has lit-

¹⁵¹ Carel, H. and Cooper, R. ‘Introduction’ in Carel, H. and Cooper, R. (eds.) *Health, Illness and Disease*, Acumen Publishing, UK, 2013, p. 4; though many have commented on the convoluted nature of this divide: for example see Kingma, E. ‘Naturalism about Health and Disease: Adding Nuance for Progress’ in *The Journal of Medicine and Philosophy*, 2014, Vol. 39, pp. 590-608; in this section I have deliberately attempted to narrow the literature analysed to those working on the ‘disease definition problem’. I did this because it is probably the largest glut of literature in the field around a single topic and therefore worthy of attention and because incorporating the work done at its edges would involve significant detours which, enlightening as they may be, I do not have space for here.

¹⁵² For a good discussion of this ‘value-free’ definition of disease, as well as the ‘value-laden’ normativist position, see Kingma, E. ‘Disease as Scientific and as Value-Laden Concept’ in Schramme, T. and Edwards, S. (eds.) *Handbook of the Philosophy of Medicine*, Springer, Germany, pp. 45-63.

tle wrong with her (presuming that a biological aversion to dairy is the only thing ‘abnormal’ about her body). These categories or sub-groups are generally referred to as reference classes.

These disease classifications are regarded as ‘value-free’ because they supposedly require no subjective decision making. Naturalist theories are argued to exist independently of normative judgement: they simply tell us whether something is a disease, not whether it is good or bad to have it. Most naturalists expand this to a two-stage process, whereby we first identify biological malfunctions (facts) and then indulge in normative discussions about what this means (whether the person is suffering, whether we should medically intervene etc.) This approach is still a naturalist position because conceptual priority is given to the objective, organic descriptions and because those descriptions are assumed to be concretely real and value free.

Across from these naturalists sit the normativists. They take a different tack regarding the objectivity of biological facts; in the case of disease they believe all classifications to be ‘value-laden’. These philosophers are placed together because their ideas promote a fundamentally subjective element to disease definition, in that they believe calling something a disease necessarily involves making a normative judgement. That is, when deciding whether or not something is a disease, we are forced to make a statement about phenomena which does not and can not speak for itself. To call upon the words of Temkin who, as so often, said it best, disease can only exist within ‘man’s moral universe, when its occurrence within a scheme of creation and right and wrong are accounted for’.¹⁵³ However, beyond these fairly vague appeals to the subjectivity and judgement involved in defining disease, it is problematic to place all normativists in the same category as the positions they promote can be quite divergent. There is enough variety and disagreement on this side of the discussion that it is questionable whether maintaining normativism as a

¹⁵³ Temkin, O. ‘Health and Disease’ in *The Double Face of Janus and Other Essays in the History of Medicine*, 1977, John Hopkins University Press, UK, p. 421.

distinct position is still worthwhile. It can mean many things to many people. It is important at this point to highlight that the general, fundamental level at which most of the disputes between naturalists and normativists take place is a conceptual one. This field is largely concerned with the theoretical nature of disease, and not with how disease is applied in a social or lay context, nor even necessarily by medical practitioners (although, confusingly, this is often presented as evidence for the desirability of choosing one theory over another). So, for naturalists, the core features of a disease relate to function and dysfunction, and for normativists these vital components are defined by some form of evaluative process. Beyond this discussion, there are numerous other positions which have been posited, a few of which are relevant here. In a 2009 paper, Marc Ereshefsky described philosophers who attempt to straddle both naturalist and normative approaches, balancing themselves gently between the two, as hybrid theorists.¹⁵⁴ Some others, such as Peter Schwartz, have tried different methods of reframing and advancing the discussion.¹⁵⁵

However, regardless of how successful they or others are in this endeavour, I will argue that they suffer from the same problems as straightforward naturalists or normativists: their project is doomed from the start to be a frustrating and difficult exercise.

Finally, a few interesting and dissenting voices have been raised which question, as I do, the value in pursuing this problem *at all*, or at least in the way that it has been done thus far. Lemoine has highlighted the ways in which this debate is positioned

¹⁵⁴ Ereshefsky, M. 'Defining 'health' and 'disease'' in *Studies in History and Philosophy of Biological and Biomedical Sciences*, 2009, Vol. 40, No. 3, pp. 221-227.

¹⁵⁵ Schwartz favours shifting from characterising concepts as they are currently being used by medical science or wider society to making proposals for new definitions, a process he calls 'philosophical explication'. See Schwartz, P. H. 'Reframing the Disease Debate and Defending the Biostatistical Theory' in *The Journal of Medicine and Philosophy*, 2014, Vol. 39, pp. 572-589.

as one of straightforward conceptual analysis, which in turn dictates the sort of theories, evidence and arguments that are permissible and constrains the possible outcomes.¹⁵⁶ His examination of the ‘rules of the game’ are a welcome excavation and I shall examine his thoughts. Hesslow famously took a stronger position, arguing that the crucial role given to possessing a disease concept is illusionary and distracting, and that the importance of such a definition to clinical practice is vastly overstated. I will restate his arguments later on in this chapter.

Elsewhere, Carel, Kidd and others have tried to break with the tradition by proposing and debating the utility of phenomenology of illness and how to align this method with long-standing philosophical traditions.¹⁵⁷ I will examine the phenomenological position at greater length below, but it is important to note that these thinkers argue from the same sense of frustration that I do. Of the conceptual inadequacy of both the medical and philosophical worlds, Carel writes:

‘Because of my training as a philosopher, my experiences pushed me to reflect abstractly on health and illness: what these concepts mean and how best to understand them. But when I started my research I found that the language and concepts routinely used to describe illness are inappropriate, incomplete and often misleading. I became increasingly aware of the impoverished language used in the medical world I encountered, which, in turn, led me to suspect that an impoverished concept of illness was in the background’.¹⁵⁸

¹⁵⁶ Schwartz also makes this point.

¹⁵⁷ See, for example: Kidd, I. J. ‘Can Illness Be Edifying?’ in *Inquiry*, 2012, Vol. 55, No. 5, pp. 496-520; Carel, H. ‘Illness, Phenomenology and Philosophical Method’ in *Theoretical Medicine and Bioethics*, 2013, Vol. 34, No. 4, pp. 345-357; Carel, H. 2014; also discussed further below.

¹⁵⁸ Carel, H. 2008, pp. 8-9

I will now give a brief description of a variety of different positions within this field, in order to give a sense of the sorts of arguments that are employed and the types of responses that could be considered representative.

Different ways to define disease

In this section I will look at some of the main ways that theorists have tried to answer the questions posed above. I treat this topic with deliberate brevity as it has been discussed extensively elsewhere and a lengthy and in-depth exploration is not necessary to make the arguments I wish to.

It is customary in this debate to start your discussion by outlining and then criticising some aspect of Boorse's naturalist position, as his is the longest standing and most disputed theory of disease. In fact, I would go as far as to say that critical interactions between definitions of disease where one theorist does not position themselves in contrast to Boorse are rare.¹⁵⁹ So central is he that Thomas Schramme adapts Nozick's comment about Rawls to say 'it can be demanded that philosophers of medicine must now either work within Boorse's theory or explain why not'.¹⁶⁰

As discussed above, his naturalism is based around dysfunction and uncovering biological facts about disease. Known commonly as the bio-statistical theory (the BST), Boorse's ideas rest on the physiology of the human body as the key to understanding disease. There are three concepts which, placed together, form the BST. The first is physiological function, which is defined as the causal contribution a system (nervous, respiratory, circulatory etc.) makes towards biological goals (sur-

¹⁵⁹ One exception being Thomas Schramme, see Schramme, T. 'A qualified defence of a naturalist theory of health' in *Medicine, Health Care and Philosophy*, 2007, Vol. 10, pp. 11-17.

¹⁶⁰ Schramme, T. 'Christopher Boorse and the Philosophy of Medicine' in *The Journal of Medicine and Philosophy*, 2014, Vol. 39, p. 565.

vival and reproduction for example). The second is the idea of a reference class, described above. These reference classes define what is considered typical for the individual under investigation. The third is a statistical concept, the idea of organic statistical abnormality, which helps to delimit pathological from normal activity. Arranged in tandem with each other, these three ideas give us a fairly clear, if not specific, notion of Boorse's theory. A disease is therefore present if there is a statistical abnormality, the result of which impairs some aspect of a person's physiological functioning and is untypical for that individual's reference class. Or, as he puts it: 'a disease is a type of internal state which is...an impairment of normal functional ability, i.e., a reduction of one or more functional abilities below typical efficiency'.¹⁶¹

These fundamental ideas and the places that they lead have been attacked for the best part of half a century. Almost every aspect of his theory has been critiqued, the most effective arguments being those which focus on the impossibility of uncovering his basic criteria in a value-free manner.¹⁶² Reference classes are not strong enough to be natural kinds and neither is physiological functioning, even dressed in evolutionary clothing, objectively easy to determine. Classic statistical issues of normality and line-drawing problems also stalk Boorse. Of further difficulty to him are several examples of diseases that seem straightforward under his classification but are not considered to be diseases in general medical contexts. Homosexuality is a case in point here, as it would appear to be unequivocally a disease state under his schema, a state of affairs very much of out step with (con-

¹⁶¹ This summary is compiled from Boorse, C. 'On the distinction between disease and illness' in *Philosophy and Public Affairs*, 1975, Vol. 5, pp. 49-68, Boorse, C. 'Health as a theoretical concept', in *Philosophy of Science*, 1977, Vol. 44, pp. 542-573 and Boorse, C. 'A rebuttal on health', in Humber, J. M. and Almeder, R. F. (eds.) *What is disease?*, 1997, Humana Press, USA; Quote is from Boorse, C., 1997. For an up-to-date summary of his position, see Boorse, C. 'A second rebuttal on health' in *The Journal of Medicine and Philosophy*, 2014, Vol. 39, No. 6, pp. 683-724.

¹⁶² For a good overview of common criticisms and Boorse's response, see: Smart, B. *Concepts and Causes in the Philosophy of Disease*, 2016, Palsgrave Macmillan, UK.

temporary) thinking. These criticisms hold especial weight considering that Boorse purports the symmetry of his theory with medical usage to be one of its great strengths.

These complaints are strong, and it is not clear that Boorse has been able to adequately account for some or any of them, though he has responded to critics periodically.¹⁶³ All that sometimes seems to hold his ideas afloat is the intuition that disease *is* related intrinsically to biology. His is, after all, the theory which ties itself most firmly to the organic and the natural. But beyond this indefatigable connection, which the majority of thinkers would like to retain, all or almost all of his arguments are contentious and have been convincingly challenged.

Nevertheless, despite these criticisms, he is still at the forefront of the field. *Why* he remains so important, so vital, so referenced, is difficult to tell. This is particularly interesting given the imbalance of support and criticism in the literature. His ideas have been rebuked and dismissed on many occasions, in a manner that in many other areas of philosophy or general academic discourse would seem adequate. George Khushf has also noted this apparent enigma, writing:

‘The scholarly response to Boorse has been vigorous and, at the same time, puzzling. Few accept his disease concept. When Boorse published a rebuttal to his many critics [in 1997], his bibliography lists well over a hundred such critics, and a literature search on the current philosophical debate indicates his work is among the most cited. Despite the broad consensus against his view, nearly everyone feels the need to return to Boorse and criticize him again. Why? This is the puzzling part’.¹⁶⁴

¹⁶³ Most notably in 1997 and 2014 - see footnote 156.

¹⁶⁴ Khushf, G. ‘An agenda for future debate on concepts of health and disease’ in *Medicine, Health Care and Philosophy*, 2007, Vol. 10, p. 19.

I can offer two explanations for this.

The first is that Boorse represents a convenient foil. His work is continually discredited because it is easy to criticise from a constructivist or loosely constructivist position which questions his basic assumptions surrounding normality and reference class objectivity and it is always nice to begin a paper with a refutation that strengthens your own position.¹⁶⁵

My second speculation is that Boorse is relevant not because of the philosophical rigour of his theories, but because these theories are the closest thing we have to a medical viewpoint. Therefore, the importance of his thought could be derived from its isomorphic relationship with practice. He himself has claimed this to be true, and it certainly should make us pause and consider the value of the BST in a different way. If this is indeed, nearer to how medical practitioners view disease, then what can we do with this knowledge? What effect might that mindset have on patients, on procedure, on insurance? Medical epistemologists know well the shortfalls of applying general theories to individuals, and it is fair to say that debates like this (i.e. what do practitioners consider disease, how do they arrive at this etc.) are common across lots of different arenas of medical decision making and knowledge production.¹⁶⁶ This, if anything, adds value and relevance to the BST: if it is not only a way of conceptualising disease but a way that disease is actually conceptu-

¹⁶⁵ Kingma argues that there is a distinction to be drawn between normativism and social constructivism, but I feel they are similar enough positions to be treated in this context as synonymous. See Kingma, E. 'Health and disease: social constructivism as a combination of naturalism and normativism' in Carel, H. and Cooper, R. (eds.) *Health, Illness and Disease*, 2013 Acumen Publishing, UK.

¹⁶⁶ Miriam Solomon discusses four possible ways in which medical knowledge is produced in Solomon, M. *Making Medical Knowledge*, 2015, Oxford University Press, UK.

alised in practice, then all sorts of interesting work can proceed.¹⁶⁷ Unfortunately, not much has been done on the BST outside of philosophy. As it is, the work remains strangely important and an obligatory introductory sentence for pretty much everyone working on the philosophy of disease who isn't Christopher Boorse.

Normativism does not have such a figurehead, but rather a multitude of theorists orbiting its own central postulate: disease is about norms. A proper analysis of health and disease suggests, to them, that what we label with these terms tells us more about our own values than it does about some biological reality. Thus, desirable states become something to which to aspire, and which we associate with health, and likewise undesirable circumstances become called diseases.

There are many general criticisms which are offered to this simplistic representation of normativism. It is too inclusive, and rather than resolving controversies, seems to encourage them (alcoholism, obesity, ageing etc. all become straightforward seeming disease states). It is too relativistic, and allows for historical (and contemporary) instances of persecution-by-medicine to be unproblematically justified. Stock examples from this criticism include homosexuals, political dissidents in the Soviet Union and slaves who ran away from plantations, all of whom were at one point considered diseased because of overt ideological biases present in their medical communities. Finally, normativism of the strongest sort breaks the intuitive bond with nature, the idea that there is some intangible or rather unquantifiable but supremely real connection between disease states and biology.

The above sketch is superficial, so to get a better idea of the sorts of arguments normativists put forward, let us look at Rachel Cooper's ideas. She sets out her

¹⁶⁷ It may be the case, in fact, that many of those who criticise Boorse do so *because* of the similarities between his view and that of the dominant biomedical model, and in criticising his position they are raising broader issues with the way that medical science classifies disease. This is not made explicit anywhere that I can see, but I nonetheless think it might be an interesting avenue of inquiry.

aims in a way that is fairly typical of normativist accounts:

‘I suggest that a neat account of disease cannot be achieved. By ‘disease’ we aim to pick out a variety of conditions that through being painful, disfiguring or disabling are of interest to us as people. No biological account of disease can be provided because this class of conditions is by its nature anthropocentric and corresponds to no natural class of conditions in the world.

I shall argue that by disease we mean a condition that it is a bad thing to have, that is such that we consider the afflicted person to have been unlucky, and that can potentially be medically treated. All three criteria must be fulfilled for a condition to be a disease’.¹⁶⁸

From here she goes on to explain each category in detail, describing how she sees her account to be more a synthesis of previous normativist writing than a novel theory of disease.¹⁶⁹ A person is sick if they have something which is considered bad to have, which allows her to negate some of the criticisms thrown at naturalists, such as the classification of homosexuality in contemporary society. Her second postulate, that a diseased person must be considered unlucky, is basically a normative version of a reference class. As she says of her definition of an unlucky individual, she is talking about someone ‘that is, roughly, worse off than the majority of humans of the same sex and age’. This allows her to skirt around the normality question and account for people with disabilities. Her final criteria is that the condition must be *potentially* medically treated. That is to say, either now or hypothetically at some point in the future, we might be able to medically intervene in order to alleviate the disease. This acts as a blade which cuts disease away from

¹⁶⁸ Cooper, R. ‘Disease’ in *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 2002, Vol. 33, No. 2, p. 271.

¹⁶⁹ Which is precisely why I feel it is a good example to discuss.

economic and social problems a person might have which would fulfil her first two categories.

Overall, her account is much more nebulous than a naturalist view would allow, and this is a problem faced by many normativist attempts. Under her ‘bad to have’ category she admits the subjective and individual nature of this description may lead to some cases where a seemingly diseased person does not think themselves to ‘have something bad’ (such as in examples of schizophrenia where individuals have vivid and enjoyable hallucinations that form a part of their identity). She tries to pull herself out of this quandary by arguing that in the great majority of cases there will be no disagreement (a statement itself open to question), but it remains a firm counterargument.

On her second point, even she admits that ‘being unlucky’ is ‘medically unsophisticated’, and I think the conceptual messiness of this argument detracts from the overall credibility of her view. Her final criteria, about potential medical treatment, seems rather indeterminate, and it’s not clear that a theory with so many overly variable components could be considered a strong conceptual challenger to a naturalist account. It is also the case, as Cooper recognises, that her schema tends towards inclusiveness, to the point where things such as unwanted pregnancy are cast as diseases. If it demonstrates one thing, this account shows us that it is easier to criticise Boorse than to suggest a viable alternative.

I hope that the above discussion has given a flavour of the sort of arguments put forward by naturalists and normativists, as well as a few of the stock critiques of such views. Clearly, I feel that both schools of thought are unsuccessful in their attempts. This is not, however, through lack of trying or theoretical sophistication, but rather because from the outset they are trying to answer an impossible question. It is to this conceptual bind that we now turn.

The reasons why definitions of disease fail

One thing that most attempts to define disease have in common is their all-encompassing nature. The very act of delimitation in this instance is necessarily one that requires completeness; the purpose of creating such a definition in the first place is to arrange phenomena neatly, or as neatly as possible, into a box labelled ‘disease’ and to make sure nothing else gets put in by mistake. Beyond the other motivations, this aim is, I believe, central to the conceptual exercise that is being engaged with here. Quite simply, there would be little point in producing a list of stipulations that was only able to demarcate certain phenomena as disease but not others. The two key assumptions made by anyone using this approach is that disease *can* be captured by a single definition and, by extension, that all diseases have some fundamental similarity.

It is true that some philosophers try to be more ‘universal’ than others: Boorse restricts himself to what he regards as medical uses of the term whereas someone like Nordenfeldt tries to explain not just human conditions but also animal and plant diseases with his ideas.¹⁷⁰ Even at their most restricted however, the theories of disease that are found in the literature are still extensive and dynamic. They are intended as a set of postulates which can be tested against our current pool of examples but which will also prove to be accurate into the future as new cases are assimilated. In theory, there is no limit at all to the number of entities they could be expected to describe. There is, then, more than a hint of universalism about them. Once formulated, these definitions *have* to be either descriptive or normative.¹⁷¹

¹⁷⁰ Nordenfeldt, L. ‘The opposition between naturalistic and holistic theories of health and disease’ in Carel, H. and Cooper, R. (eds.) *Health, Illness and Disease*, 2013, Acumen Publishing, UK.

¹⁷¹ Lemoine draws this distinction as one between ‘description’ and ‘stipulation’ but our uses are similar.

That is, they have to either be an attempt to describe what disease means within socially existing parameters - be it medical uses of the term, intuitive interpretations of 'undeniable' disease or some other broad categorisation - or they are a suggestion of way in which we might define disease for whatever purpose. On the whole, it would seem that most of the theories thrown around in this debate are trying to be descriptive. They are attempts to articulate succinctly a pre-existing category of things, which is commonly recognised and frequently encountered but currently ill-defined. However, a purely descriptive approach clashes with some of the aims described above (resource allocation, diagnostic clarity etc.), which suggests that there must be a normative element involved if any theory is to fulfil these objectives. In any case, both of these possibilities (descriptive and normative) are, I believe, doomed to fail. I will deal with these two options in turn and examine why they might not be successful.

Starting with the descriptive option, it is clear that the majority of disease definition literature purports to be at least partially descriptive. Certainly, many theorists draw extensively on examples of disease to support their ideas and use the same reservoir to attack their opponents. A counterexample, drawn from either the real-world or a similar but hypothetical world, that does not accord with a theory is the most common form of criticism offered. At the very least, the best indicator that we seem to have of the strength of a theory of disease in this context is the extent to which it accurately accords with some external map of disease which preexists in the world.

In response to this I put it that there are simply too many *things* that count as disease for this to ever be a successful project. Even within a strictly confined theoretical space, the vast magnitude of different types of entities that could make a claim to disease status is staggering. It is not so much that there are so many diseases as it is that there are so many ways of thinking about disease and so many ways that disease is thought about. If we were to try and, as some do, strip away from the

fatty edges of disease all common usage of the term and cut from the centre some form of solid terminology only used by medical professionals, I still believe we would be left with this problem. Different areas of medicine deal with disease definition in a variety of ways. Disease can exist on a spectrum between normal and pathological or as the presence of a particular bacteria or because of the discovery of certain cells. It may be purely symptomatic. It can be acute or chronic, universal or extremely rare. Sometimes what may be disease in one individual is not a disease in another. Sometimes what may be disease in one culture is not a disease in another. Most diseases appear to be harmful, but not all are. Having a disease may prevent another disease. Some diseases can be fully subsumed into a biomedical causal matrix, but many can not. This indeterminacy goes on. What is important here is that both the conventional, common-language usage of the term and more specialist application produce a hopelessly manifold array of entities. Indeed, this is precisely the reason why counterexamples are so often employed in the disease definition debate: because there is an incredibly diverse set from which to draw from, and there is simply no way of accounting for all of them without falling into the trap of including that which appears clearly to not be disease. We can define diseases, and do so regularly, using a number of different methods depending on the purpose of our criteria, but we cannot define disease.¹⁷²

To my mind there is no better evidence for this position than the inability of philosophers to make progress on this problem over a fairly long amount of time. As Kingma states, ‘thirty years of literature has failed to deliver an answer’ to the disease question.¹⁷³ I would state this in even firmer terms: the debate has di-

¹⁷² The retort to this might be that the ICD-10 appears to do a good job of defining disease. I would say that this is indeed true, but it is constructed on a case-by-case basis rather than an essentialist one. There are no necessary criteria for being included but there is a staggering amount of diversity.

¹⁷³ Kingma, E. 2013, p. 37; depending on how you frame it, this is also of course a far older debate.

gressed in a few different directions but the fundamental issues remain the same, remain fundamentally unresolved and there is little to suggest that this will change through the continued use of current methods. It may be that the reason so little ground has been made is because ‘the concepts of health and disease have become problematic in ways that are unprecedented’.¹⁷⁴

This is owing to, amongst other things, the rise of economic and social protection for those with diseases, the challenging of normality and perceptions of pathological states by disability campaigners, the growth of patient groups, the discussion around enhancement, sex change operations and the increasing medicalisation of previously non-medical conditions. But even if this is the case, a rapidly changing medico-social environment underlines further the futility of attempting a statement of complete conceptual containment, especially as philosophers are not on the whole trying to provide a snapshot but rather something more dynamic. If historical and hypothetical examples are to be employed as counterexamples, then it is reasonable to expect that a condition of a theory is that it not only apply to the present but also to the past and the future.

Schwartz has made a similar point to those described above, contrasting scientific reality with the essentialist aspirations of philosophers:

‘As scientists have acquired better and better understanding of diseases and their causes, they find not a unifying microstructure, as for gold or water, but variation. While many have sought an essence that all and only diseases share, this quest has been blocked at every step by variability and heterogeneity. Any definition that would draw a sharp line through all conditions, determining for each whether it is a disease or not, looks like the imposition of a decision, rather than the application

¹⁷⁴ Cavel, H. and Cooper, R. 2013, p. 2.

of a discovery'.¹⁷⁵

What Schwartz is hinting at here is that the philosophy of disease has proceeded on the basis that diseases are natural kinds of some form or other.¹⁷⁶ Whilst this is an angle that has been used to attack naturalist conceptions of disease, most notably by Reznek, I would like to employ it here to criticise the heart of descriptive theories of disease: their reliance on a regularity and uniqueness to diseases that does not seem empirically sound.¹⁷⁷ This regularity is admittedly twofold. Naturalists appear to presume a physical, biostatistical reality to disease which is easy to criticise as a natural kind argument, and has been so, as I have described above. Normativists do not believe in this form of measurable unity, and indeed it is this which in many ways separates them most from naturalists. They do however, also lean upon a different sort of universalism: that there is enough consistency in our agreed set of disease examples (and indeed that enough of us agree on said examples) that it is possible to design a framework capable of capturing them without capturing anything else.

Now, this consistency might have little to do with microbiology, pathophysiology, evolutionary function, variations from a norm etc. but it nonetheless requires the presence of some underlying and particular quality or qualities, which are found in diseases as mediated by us and not in non-diseases. Thus is it that in the standard normativist approaches, their routine stipulations (causes harm, unlucky for the

¹⁷⁵ Schwartz, P. H. 'Decision and discovery in defining "disease"' in Kincaid, H. and McKittrick, J. (eds.) *Establishing medical reality: Essays in the metaphysics and epistemology of biomedical science*, 2007, Springer, UK, pp. 47-63; it might be stated that this underlying diversity is a key feature of biology as a whole, not just disease.

¹⁷⁶ There are gradations on this position. Rachel Cooper for instance argues that individual diseases are natural kinds, but that disease as a whole is not: Cooper, R. 'Natural Kinds' in Fulford, K. W. M. (ed.) *The Oxford handbook of philosophy and psychiatry*, 2013, Oxford University Press, UK.

¹⁷⁷ Reznek, L. *The Nature of Disease*, 1987, Rutledge and Kegan Paul, USA.

individual etc.) *become* the universal features of disease. It is just that these concrete features are framed as instrumental rather than statistical or structural, and the level of discovery is moved from the actual world, or 'the facts', to the tools we use to uncover them. Both naturalist and normativist theories of disease are then to some degree universalist schemas.

So, what if we change the intention, then, and say that these theories are not meant to be descriptive, but rather normative? They might still reasonably gain some credibility from descriptive accuracy, but largely their success would be found in their ability to achieve some predetermined goals, such as reducing diagnostic creep or resolving controversial cases. An example of this is the work of Thomas Schramme, who argues that naturalism can provide us with a fairly stable and useful concept of disease which is a necessary guard against medicalisation. In fact, Boorse's original intention was to kick back against what he called the 'psychiatric turn' under whose influence medicine was, in his view, dangerously encroaching on the territory until then occupied by social morality. Another advantage of reformulating disease definitions as normative exercises is that they are freed from the vast magnitude argument discussed above: if you are stating what *should* be rather than what *is*, then you are apparently no longer tied down by the tyranny of examples. However, you still have to provide a justification for your theory - as to why it is a good way of classifying phenomena, what we gain by organising things in this way and how exactly this would work in practice. It is here that this normative framing fails to convince.

It is rare to see explicit justification given to the usefulness of choosing one model or theory of disease over another. The benefits of possessing a clear concept of disease in general are often highlighted, but very little space is afforded to justifying the adoption of one particular view in light of its non-descriptive advantages. The one salient factor that splits theories is their relative ability to accurately reflect intuitive feelings about what disease is and what a disease looks like, *not* any values

relating to applicability or outcomes. So in fact, defining disease is often more like a clever parlour game than a debate with implications for real life. When Caplan spoke about the philosophy of medicine being removed from practice, this is what he had in mind.

Yet there are times when philosophers have stated, or at least hinted at, normative aims. Whilst Boorse maintains for the most part that his account is a descriptive one, and uses the Standard Nomenclature of Diseases and Operations as a guide by which to judge his success, he also stipulates that some universal conditions such as periodontal disease should not be considered disease states, which belies a normative aspect to his work.¹⁷⁸ Cooper too highlights a notable discrepancy between her theory and existing convention by arguing that ‘we still think of unwanted pregnancy as not being a disorder because our intuitions lag behind changes in the disorder-status of a condition’, suggesting that there is at least some element of her thinking which is out of step with common assumptions but simultaneously not a problem for her theory.¹⁷⁹

What is more important than this however, is that even if philosophers of medicine *were* solely concerned with the practical application of their ideas, and presented theories as explicitly designed to capture disease in a socially useful way, it is highly doubtful that they would be very successful in challenging and changing medical practice. Medicine, for all intents and purposes, defines disease. Individuals are tested and diagnosed and treated in their hordes daily. A longstanding, sophisticated and, though fragmented, effective infrastructure exists across the world to do precisely that. There is nothing to suggest that a universal theory of disease would have any great effect on clinical medicine and so if no-one is listening, should we talk?

¹⁷⁸ The Standard Nomenclature of Diseases and Operations is published by the American Medical Association.

¹⁷⁹ Cooper, R., 2003, p. 278

A hypothetical example might make this point clearer. Say, for whatever reason, a 'new' disease emerged. Social infrastructure begins to coalesce around it: patient advocacy groups are formed, conferences are held, medical responses are researched. In countries with largely private healthcare systems, insurance companies sit up and take notice - is this something they should be covering? Now, this condition is controversial and potentially expensive. People who believe they suffer from it clash with individuals who deny them. Who would we look to in order to solve this controversy and to resolve the conflict? Which bodies carry epistemic and ontological authority in these situations? Certainly not, under current conditions, philosophers. It is difficult to conceive of a situation where a new illness would be cross-referenced with some list of philosophical stipulations in order to decide whether or not it was adequately disease-like.

This is not to say that philosophy cannot speak to and help us understand medicine, or that it cannot gently nudge and cajole the dominant modes of thinking. It is just that in this specific circumstance - formulating a self-contained theory of disease - any claim to practical consequences are likely overstated. Diseases, on the whole, are already defined adequately, and those that aren't are unlikely to be helped by a universal theory of disease. This is because an essentialist proposition that emerges from a theoretical, philosophical base has no credibility in competition with definitions that grow out of biomedical structures. It will not carry more weight in controversial cases than medical opinion or patient views.

A contrast can be drawn here between the philosophy of medicine and bioethics (which is a distinction that Caplan also makes). The history of the latter in the second half of the 20th century and the fledgling decades of this one serves to remind us how influential and important reflective, philosophical thought can be.

Bioethics, in all its complicated permutations, reframes classic ethical questions and brings arguments to bear on cases as they develop. Sitting as it does at the intersection between medical practice, theory and law, this is a discipline fully inte-

grated to other cognate areas of study and administration.

In the International Bioethics Committee, it possess a forum whose authority is recognised worldwide and all of the UNESCO member states have adopted the Universal Declaration on Bioethics and Human Rights, which was unveiled against a backdrop of a 'great number of existing international guidelines, statements and declarations relating to bioethics'.¹⁸⁰ Since membership of UNESCO stretches to 195 countries, this is a sizeable achievement in terms of global influence. There are also many declarations which deal with more specific areas of the discipline, such as the UN Declaration on Human Cloning or the UNESCO Universal Declaration on the Human Genome and Human Rights.

The movement has been criticised - (though what movement is without critics) - but these criticisms are levelled at its intrusiveness into scientific autonomy, the correct level at which to administrate conventions, whether a certain body or other possesses a mandate to grant it authority, the effectiveness of non-binding declarations etc., and not aimed at its core relevance. The fact remains that bioethics sits in sharp contrast with the philosophy of medicine as an academic subject that has an impact on behaviour and alters policy whilst remaining in large part a theoretical, normative discipline driven by a long history of deep thinking.

The road to influence and to relevance may well be harder for philosophers of medicine. It is not immediately obvious in which ways they can and should assert themselves, as recent historical precedence is lacking. Some things are clear though. The temptation to remain insular in our work, to offer critique without broader vision, is one which must be consciously avoided and different questions must be asked in order to return to the realm of relevance. As I cover this in more detail at the end of this chapter, for now we will return to the topic at hand.

¹⁸⁰ Andorno, R. 'Global bioethics at UNESCO: in defence of the Universal Declaration on Bioethics and Human Rights' in *The Journal of Medical Ethics*, 2007, Vol. 33, No.3, p. 150.

In this section I have argued that any universal theory of disease is necessarily either descriptive or normative, and that both approaches, whether actual or hypothetical, fail. This is because there exists too much diversity in what people consider to be disease entities and because there is no suitable justification given that would likely influence medicine to accept and adapt to normative suggestions made by philosophy. You either say what *is* and you're wrong or you say what *ought to be* and nobody listens to you. However, I am not the first to critique this field, and other theorists' views strengthen my argument.

A longstanding criticism that covers some of the same ground as I have come from GERMUND HESSLOW, who in 1993 asked the question 'do we need a concept of disease?'.¹⁸¹ His central argument is that the importance of possessing a clear disease concept is illusory and that philosophy's obsession with this 'conceptual straight-jacket' obscures the fact that it makes very little difference to clinical decision-making. What he contends is that since we treat things that aren't diseases and don't treat things that are, as well as provide medical provision to some degree based on economic grounds, then the best way of formulating medical decision-making is as a cost-benefit analysis, rather than anything crucially reliant on a universal view of disease. His central point is well made: having a clear definition of disease as a whole is not essential to medical care, where other factors take precedence.

Some thinkers have suggested problems within this field are largely caused by the constraints of the conceptual analysis used to try and answer the original question. As Leen De Vreese has argued, due to the extreme difficulties present in conceiving an univocal meaning of disease, deciding to privilege one theory over others automatically leads to a revision of at least some of our use of the concept whether we want it to or not (because no theories can fully account for 'disease' as it is

¹⁸¹ Hesslow, G. 'Do we need a concept of disease?' in *Theoretical Medicine*, 1993, Vol. 14, No. 1, pp. 1-14.

now).¹⁸² She goes on to say that the ‘only possible justification’ for preferring one theory to another has to be one based on pre-existing intuitions about disease rather than normative projections. The tension between these two demands renders the type of definition that is being aimed at impossible. As she explains:

‘Presuppositions with respect to what diseases are will always form the basis for building and/or accepting a specific definition. Indeed, one cannot deny that all proposed definitions are based on presuppositions on what is a disease and what not, and hence that an a priori definition on the basis of which one can subsequently decide what is a disease and what not, cannot be given’.¹⁸³

De Vreese concludes that this impasse will not be overcome through the methods currently employed. Her main aim in highlighting the deficiencies of the current approach was to encourage others to try new methods and embrace new ways of thinking, somewhat of a theme in this chapter.

Lemoine has also attacked conceptual analysis as an appropriate set of tools for addressing disease. I will examine his ideas in more detail below when I discuss the negative consequences that have been experienced by the field as a whole from pursuing such an approach. But first I will add a further two, broad criticisms.

Epistemic homogeneity and the mental/physical distinction

The first of my two criticisms is that disease definitions make assumptions about epistemic homogeneity which are not accurate and downplay important aspects of

¹⁸² De Vreese, L. ‘Rethinking the concept of disease debate: a pragmatist alternative’, Centre for Logic and Philosophy of Science, draft copy accessed online 2/04/16 http://logica.ugent.be/centrum/preprints/Rethinking_the_concept.pdf.

¹⁸³ Ibid., pp. 6-7.

medical conflict, especially in areas where a clear-cut disease concept is supposed to be useful. Because the thinkers in this field are so fixated on the ‘what’ of disease, there is little space given to the ‘how’ and the ‘who’. This is an especially worrying oversight given the fact that who gets to define the disease and how they do it are often the more pressing questions in the more controversial cases.

The second is that they rely too heavily on being able to easily distinguish between physical and mental illness and do not reflect enough on the difficulty of this distinction. Naturalist positions seem to assume that this division is uncomplicated and that they can focus purely on physiological conditions without having to justify or explain this categorisation. Normativist positions often emphasise the value-laden nature of many psychological diseases, whilst giving precedence to the role of medical science to identify and legitimise illness. My issue with this is that a biomedical view underlies both positions and as a consequence the theories are unable to adequately explain the many conditions which do not fit neatly into these categories. Contrary to the sharp dichotomy that is often drawn between naturalists and normativists, this is an area where they share many of the same assumptions.

Khushf has argued strongly for this view. He compared Nordenfelt and Boorse, positioning them as archetype naturalist/normativists, stating that:

‘...both are actually working toward similar ends. Both advance health concepts that seek to tease out fact from value, and reinforce theoretical and social structures that insulate medical science from outside intrusion and distortion. In different ways, both reflect the thought style of modern medicine itself, and both work to preserve its core features’.¹⁸⁴

¹⁸⁴ Khushf, G. 2007, p. 20; he borrows the concept of ‘thought style’ from Ludwig Fleck.

He goes on to argue that maintaining a fact/value distinction in our analysis of medicine and disease concepts is likely to become impossible in future, given the material changes to medical infrastructure.¹⁸⁵ But what is important here is his highlighting of assumptions about medical authority, about scientific descriptive ability and about the desire to protect or isolate medicine from the messy value structures of a dynamic and diverse society.

Within this, one of the assumptions that philosophers make when trying to define disease is that there is a workable level of agreement within either medical science (if you are a strict naturalist) or societies as a whole (if you are a normativist) relating to disease states. Without this homogeneity, we would be unable to say that having something deemed undesirable is potentially a disease, because only certain people might think it to be the case. It is true that in many instances, our ‘intuitions’ about disease are relatively consistent across medical and lay populations, and so comparing some theory of disease against a list of examples like cancer, tuberculosis, typhoid etc. is straightforward. In these instances, it makes sense to proceed on the basis that there is an uncontroversial set of cases with which to test our ideas. However, there are enough examples where this is not true to make us think twice about this approach.

In these situations, disagreements and discord ring out between doctors, patients and lay individuals. Philosophers of medicine who propose theories of disease bestow upon us with few tools to understand these conflicts.

Let us examine a case on the fringes of medical legitimacy to demonstrate what I

¹⁸⁵ Khushf views the clinical/administrative divide as the embodiment of this distinction, and cites recent structural changes to health care provision as evidence that the philosophy will likewise evolve.

mean.¹⁸⁶ ‘Morgellons’ is a condition that has ‘no general medical acceptance as a disease entity’.¹⁸⁷ However, it does have symptoms. Primarily, the location of discomfort reported by patients is on, in, or under the skin. Individuals complain of painful and frustrating sensations of a stinging, crawling, itching nature. These irritations are accompanied by raw cutaneous lesions which fail over time to heal properly. Alongside these dermatological problems, a host of other issues may be present. Fatigue, joint pain, difficulty remembering words and speaking, headaches and other non-specific symptoms are recorded by patients. Unsurprisingly, perhaps, there is also a high incidence of related conditions that morgellons patients also suffer from including chronic fatigue, depression, OCD, ADHD, fibromyalgia, joint pain, sleep problems, hair loss and neurological disorders as well as anxiety and substance abuse/dependence.¹⁸⁸ The number of patients who suffer from comorbid psychological conditions has been reported as high as 75%.¹⁸⁹ The relationship between these comorbid features is disputed. Whereas patients argue that these conditions are symptomatic of morgellons, doctors are more likely to believe that the link between them is correlative.

The most contentious aspect of morgellons is the wrangling between doctors and

¹⁸⁶ This section is based on a previous work: Quinn Schone, H. ‘Learning from Morgellons’, pp. 4-6, https://www.ucl.ac.uk/sts/prospective/msc/Quinn_Schone_2014_Learning_from_Morgellons.pdf archived on 19/07/17 at <http://www.webcitation.org/6s6JW-B0Bt>.

¹⁸⁷ Mayne, P., English, J. S., Kilbane, E. J., Burke, J. M., Middelveen, M. J. and Stricker, R. ‘Morgellons: a novel dermatological perspective as the multisystem infective disease borreliosis’ in *F1000Research*, 2013, Vol. 2, No. 118, doi:[10.12688/f1000research.2-118.v1](https://doi.org/10.12688/f1000research.2-118.v1).

¹⁸⁸ Savely, V. R., Leitao, M. M. and Stricker, R. B. ‘The Mystery of Morgellons Disease: Infection or Delusion?’ in *American Journal of Clinical Dermatology*, 2006, Vol. 7, No. 1, p. 2; Ahmad, K. and Ramsay, B. ‘Delusional Parasitosis: Lessons Learnt’ in *Acta Dermato-Venereologica*, 2009, Vol. 89, p. 167; Hylwa, S. A., Foster, A. A., Bury, J. E., Davis, M. D., Pittelkow, M. R. and Bostwick, J. M. ‘Delusional infestation is typically comorbid with other psychiatric diagnoses: review of 54 patients receiving psychiatric evaluation’ at Mayo Clinic in *Psychosomatics*, 2012, Vol. 53, No. 3, pp. 258-65.

¹⁸⁹ *Ibid.*, p. 264.

patients over aetiology and one symptom in particular. Patients consistently report the existence of protruding material from the skin and blame this for the painful sensations they experience and the sores that develop. Often described as ‘fibres’ or ‘filaments’, these ‘protruding’ items can normally only be viewed through a microscope.¹⁹⁰ Patients have reported these fibres as being of varying length, colour and transparency.¹⁹¹ This belief is regarded as the ‘distinguishing characteristic’ of the condition by patients and a small number of researcher advocates.¹⁹²

However, in clinical settings, Morgellons sufferers have consistently been diagnosed as possessing delusions of parasitosis, an age-old condition that has been recognised for over a century. Delusions of parasitosis, delusional infestation or Ekbom syndrome is a psychological condition where individuals falsely believe that there are insects, parasites or other unidentified objects about their person and most frequently under their skin which cause them discomfort.¹⁹³ Under this interpretation of Morgellons, which is now favoured by the majority of doctors, the open wounds that patients present with are self-inflicted in the process of trying to relieve their symptoms, the fibres in most cases come from clothes and the environment and the

¹⁹⁰ For images of these occurrences, see: http://morgellonsdiseaseawareness.com/morgellons_photo_galleries/morgellons_fibers_in_skin archived on 19/07/17 at <http://www.webcitation.org/6s5FGiP2x>.

¹⁹¹ Savely, V. R., Leitao, M. M. and Stricker, R. B. 2006 p. 2.

¹⁹² <http://www.thecehf.org/about.html> archived on 19/07/17 at <http://www.webcitation.org/6s5FZtNQx>.

¹⁹³ Bak, R. *et al* ‘A review of delusions of parasitosis, part 1: presentation and diagnosis’ in *Cutis*, 2008, Vol. 82, No. 2, pp. 123-130; Edlich, R. F., Cross, C. L., Wack, C. A. and Long, W. B. 3rd ‘Delusions of parasitosis’ in *The American Journal of Emergency Medicine*, 2009, Vol. 27, No. 8, pp. 997-999; Levin, E. C. and Gieler, U. ‘Delusions of parasitosis’ in *Seminars in Cutaneous Medicine and Surgery*, 2013, Vol. 32, No. 2, pp. 73-77.

comorbid features a function of someone predisposed towards mental illness.¹⁹⁴ In essence, then, according to mainstream medical opinion, morgellons is an old disease dressed up in new clothing. It has been suggested that the alternative disease model which strays from the medical account was galvanised by advances in communications technology, most notably the internet, which allowed patients to converse with each other and form concrete, non-medical aetiological narratives. But also in play here are a group of patients desperate not to be labelled as psychologically ill and extremely adverse to any suggestion that they might be. To them, a psychological diagnosis does nothing but tug the validity of their pain from under their feet.

So, in an instance like this, what are reasonable expectations for a definition of disease? Well, one of the claims made by philosophers is that their ideas may be able to resolve controversial cases by distinguishing disease from nondisease, so perhaps a theory might be able to tell us whether morgellons is a disease. If we take some of the philosophers we have already examined and apply their ideas to this case, I think it becomes apparent that they possess severe shortcomings. Beginning with Boorse, it is simply unclear as to whether this would be classified as a condition or not. There would seem to be a distinct dysfunction with reference classes, but there is a lack of the kind of biological statistical deviation to which he is so fond.

Though at several points during his work he states that his theory is only applicable to physical illness, he never provides firm demarcation criteria by which to divide the two. He also states that criticisms of his work are only relevant if they refer to 'medically clear cases', which indicates he has little time for the vagaries of some-

¹⁹⁴ The hardening of medical opinion on the side of a delusional disorder was especially evident following the publication of a CDC report that found no organic signs of pathology: Hylwa, S. A., Foster, A. A., Bury, J. E., Davis, M. D., Pittelkow, M. R. and Bostwick, J. M. 2012, pp. 258-65; Pearson, M. L., Selby, J. V., Cantrell, V., Braden, C.R. *et al* 'Clinical, Epidemiologic, Histopathologic and Molecular Features of an Unexplained Dermopathy', 2012, in *PLoS ONE* 7(1): e29908. doi:10.1371/journal.pone.0029908; Freudemann, R. W. and Lepping, P. 'Delusional Infestation' in *Clinical Microbiology Reviews*, 2009, Vol. 22, No. 4, pp. 690-732.

thing like morgellons. As such, in this instance, it is fairly uncertain as to what his ideas tell us at all.

Normativist ideas seem more straightforward in this circumstance. Under Cooper's schema, as discussed above, we can see that for a patient, having morgellons would be a bad thing, we would consider the person to be unlucky and their condition would be potentially treatable by medicine. Morgellons, then seems largely unproblematic: it is a disease. Clearly, this fails to explain or resolve the enormous controversy surrounding the condition.

If we use some other definitions, we see similar patterns emerge. So, Scadding's idea of 'biological disadvantage' renders morgellons a disease because it is true that patients struggle in relationships, their employment prospects are damaged by their condition and their reproductive chances are impaired (his criteria).¹⁹⁵ Wakefield's influential account defines disorders as 'harmful dysfunctions', and tries to incorporate both a value-laden and factual component into our understanding of the concept.¹⁹⁶ Viewed through the lens of this theory, morgellons would certainly fulfil the 'harmful' portion of the criteria, seeing as it is 'judged negative by socio-cultural standards' and 'harmful according to social values'.¹⁹⁷ It is less clear whether it would qualify as a dysfunction, which in this instance is close to Boorse's use of the term. Wakefield describes a dysfunction as a 'scientific and factual term based in evolutionary biology that refers to the failure of an internal mechanism to perform the natural function for which it was designed'.¹⁹⁸ There is not the space here to examine in all its nuances the implications of this definition, but I think it is

¹⁹⁵ Scadding, J. G. 'The semantic problems of psychiatry' in *Psychological Medicine*, 1990, Vol. 20, No. 2, pp. 243-248.

¹⁹⁶ Bolton, D. 'The usefulness of Wakefield's definition for the diagnostic manuals' in *World Psychiatry*, 2007, Vol. 6, No. 3, pp. 164-165.

¹⁹⁷ Wakefield, J. C. 'The Concept of Mental Disorder' in *American Psychologist*, 1992, Vol. 47, No. 3, pp. 373-388.

¹⁹⁸ *Ibid.*, p. 374.

certainly arguable that morgellons, whether a little understood neurological condition, a dermatological concern, a psychological maladjustment or something even more ambiguous, goes some way to fulfilling his criteria.

What these (and other) theories of disease have in common is that they add very little to our understanding of cases like this. There is no explanation for the competing interests, the various complicated ways that people feel delegitimised, the alternative aetiologies and why they are believed. Nothing can be extrapolated which might unpick the value disputes present or the power structures which enable them, the way that patients and doctors view disease entities or the heterogeneous responses of individuals and professionals to confusing symptomatic presentation. In short these theories *say* nothing interesting, new or useful about morgellons, or indeed many other conditions that find themselves in the same category. It is not whether morgellons or fibromyalgia or whatever are diseases that is really at stake here, but rather how they are diseases and on whose terms.

In this section I have criticised at length the efforts of various philosophers to define disease in a self-contained manner. I have presented arguments against *any* general theory of disease being successful, by positing that the number of entities hoped to be sufficiently delimited is too great and by putting it that normative theories lack adequate justification. Further to this, I looked at similar critiques from others and raised some questions about that which is left unasked by theories - namely questions about epistemic authority and the true roots of controversy in disease definition. There are, however, more things to say on this topic. Not only do I believe that the literature suffers from major flaws, but that the approach taken by many theorists has unintended consequences of a negative nature. It is at these I will now look.

Consequences of such an approach

It is generally accepted that philosophers working on the disease definition ‘problem’ are engaging in a form of conceptual analysis.¹⁹⁹ That is, they are trying to agree upon a cogent definition for a well known terms, as well as uncovering the exact relation between them. In this case, the terms are ‘health’ and ‘disease’ as well as, on occasion, ‘illness’, ‘injury’, ‘disorder’, ‘dysfunction’ etc., though in this section I have focused on ‘disease’ as a central concern. The method of honing our definitions generally proceeds as follows: a set of uncontroversial examples are treated as foundational, and a list of criteria is drawn up in the form of necessary and sufficient conditions which capture to a great degree these examples. A proponent then argues why their stipulations are the most accurate, anticipates counterexamples and controversial cases and adds any further justifications that they deem relevant. Any opponent wishing to join the conversation must then either attack their definition, propose a new one or do both. I believe that setting up the ‘rules of the game’ in this manner has a nefarious effect on the sort of philosophy that is produced subsequently.

In this section I will argue that decisions to pursue such an approach limit problem selection and centre the discourse around narrow questions of internal consistency and accurate isomorphism to an agreed set of examples, at the cost of moving the philosophy any closer to practice, patient experience or some other practical measure. The way in which the leading figures in a field conduct their debates colour and direct the rest: it gives a shape and a flavour to the philosophy that others must either replicate or give firm justification as to why they are taking a different path. Most often, they slip into the conversation and follow the established norms, ‘having a go’ as it were at producing their own definitions to add to the pot.

¹⁹⁹ I have adapted this short section from Lemoine’s description in Lemoine, M. 2013, p. 311.

Lemoine has argued along these lines, stating that the most influential figures in this field follow the same rough rules, engaging with each other on the basis of fundamental understandings about the kind of theories that would be considered successful. However, this leads to a situation where more than one theory could be regarded as reasonably successful and arguments ‘about conceptual analyses of “health” and “disease” consist mainly in providing uncontroversial counter-examples to a definition of a term that should successfully account for them’.²⁰⁰ This is a problem because it highlights the shortcomings of using conceptual analysis, demonstrating that it is not sufficient in its current form to actually decide between theories. Therefore, he argues that the naturalism/normativism debate will not be resolved in this manner because both sides may feel justified in thinking that they have produced relatively successful definitions of disease and there is nothing we can reach for that would privilege one account above the other. Worryingly, because of the potential to just keep producing and tweaking theories, this is a situation which left unchecked could continue ad infinitum, albeit in various permutations. His rather devastating pronouncement is that the *only* definitions that conceptual analysis can completely rule out are ‘those that nobody would hold, because of some counterintuitive consequence nobody would support’.²⁰¹

Lemoine goes on to argue for a potential way of deciding between naturalism and normativism that goes beyond conceptual analysis, namely calling for the naturalization of the concept of disease, a process he has detailed elsewhere.²⁰² However, for our purposes here, his vital contribution is the way in which he so plainly lays out the various internal mechanisms of conceptual analysis in relation to disease definition and demonstrates the ultimately limited usefulness of such an approach.

²⁰⁰ Ibid., p. 316.

²⁰¹ Ibid., p. 320.

²⁰² Lemoine, M. ‘The Naturalization of the Concept of Disease’ in Huneman, P. *et al* (eds.) *Classification, Disease and Evidence*, History, Philosophy and Theory of the Life Sciences 7, 2014, Springer, USA pp. 19-41.

What he picks up on which I would like to expand is the use of counterexamples as a major form of rebuke. I believe that too often the energy expounded by philosophers on the search for a perfect case with which to deliver the knockout blow is a wasted effort. Because though other types of arguments are employed by thinkers, counterexamples are king. However, for the most part, they distract and divert attention from more important matters.

If you are aiming to refute a theory of disease then there is no better way of doing it than to produce an example which quite clearly does not accord with both our intuitive notion of disease and the stipulations provided by your opponent. In some circumstances, it is the criteria themselves which are attacked rather than their consequences, but since the matter in which they are disputed is similar I also include them here. Luckily for philosophers indulging in this kind of attack, there are so many applicable entities to choose from, both real and potential, that often this is a case of just picking the right one off the shelf to fit your argument (see example below). However, this can lead to some bizarre lines of inquiry which, rather than necessarily engaging with the literature in a critically useful way, make the debate entirely about internal logical cogency. Though this doesn't sound like a negative charge, its effect is to drag the discussion further from practice and into ever smaller, ever more irrelevant avenues of discourse. Philosophers consciously operate within a paradigm and their acceptance - sometimes an explicit agreement, sometimes an acquiescence - to the rules of this arrangement is dictating the type of philosophy that gets done.

A good example of this is Rachel Cooper's discussion of Boorse.²⁰³ She attacks his theory on two fronts, namely that his ideas rely on the existence of both natural kinds and clear-cut evolutionary rules of functionality, which, according to her, do not exist in this instance. To support this statement she employs a number of examples. The first of these is actually an extension of an argument used previously

²⁰³ Cooper, R. 2002, pp. 263-282.

by Wright, which is that a Boorsean account of function cannot distinguish accidental from non-accidental contributions to the goal of a system. So, while sweating has the function of cooling down the body and contributing to the goal of regulating body heat, general survival etc., should you trip and knock a bucket of cold water over yourself that would perform the same role.²⁰⁴ As we cannot tell the difference between the two, something in Boorse's analysis must be lacking.

To continue with Cooper's critique, her second line of contention is with the notion that it is possible to draw up reference classes in any practical way, which is necessary if we are to define dysfunction in the way Boorse wants us to. Cooper argues that due to human variation these would have to be excessively small, in some cases consisting of just one individual, such as 'elderly female Masai mountain-bikers [or] half-Chinese, half-Eskimo boy toddlers'.²⁰⁵ As to not single out Rachel Cooper, I will look at some others, for there are many who engage in similar, lengthy discussions of potential shortcomings which can be exposed through clever counterexamples. Lilienfeld and Marino discuss Wakefield in much the same way. Looking in detail at his theory and focusing on the role that evolution plays in culture, they argue that Wakefield's ideas fail to adequately account for exadaptions. They therefore put forward criticisms like the following: 'atheists who are persecuted and ostracised as a result of their beliefs (and thus experience harm) would in many cases be considered disordered according to Wakefield's criteria because, as noted earlier, religious beliefs are probably adaptively neutral exadaptions rather than adaptations'.²⁰⁶

What these arguments have in common is their logical accuracy and their practical

²⁰⁴ Ibid., p. 5; Wright, L. 'Functions' in *Philosophical Review*, 1973, Vol. 82, pp. 139-168.

²⁰⁵ Cooper, R. 2002, pp. 6-7.

²⁰⁶ Lilienfeld, S. O. and Marino, L. 'Mental disorder as a Roschian Concept: a critique of Wakefield's "harmful dysfunction analysis"' in *The Journal of Abnormal Psychology*, 1995, Vol. 104, No. 3, p. 413.

uselessness. They are both philosophically sound and not fit for purpose. This is because they do not shift the debate in any meaningful way, and continue to point the search-light at component parts of theories rather than the whole beast: the types of theories we produce and the way that we produce them. These criticisms act, in my view, like playful distractions from more important matters - no-one outside philosophy considers the function of a bucket of water accidentally spilled to be comparable with sweating, just as nobody believes that atheists who are discriminated against are ill.

A good way of analysing this is to use Illari and Russo's taxonomy of counterexamples. They compiled a set of counterexamples commonly used by philosophers in debates and ordered them in a hierarchy from the broad to the precise. These range in scope from 'all possible worlds' downwards through 'worlds close to the actual world', 'this world', 'some region of this world' to 'some region of this world at some time'.²⁰⁷ At the broader end of these possible counterexamples, critics can draw upon hypothetical situations from any conceivable environment, as long as they are consistent with the original argument (on the same 'plane' so to speak). Closer to the bottom, counterexamples must be found from the world as it is, some more specific area of the world, or a specific area of the world at a specific time. As may already be clear, the discussions around disease definition currently take place on a 'worlds close to this world' basis, hence the inclusion of elderly female Masai mountain-bikers and sufferers of persecuted atheist disease.

I believe that a shift towards something more local would be beneficial, as this would more readily recognise the temporal and contextual nature of all of our philosophical understandings of disease. The way illness is mediated is, I would argue, entirely context dependent, and our philosophical discourse should reflect

²⁰⁷ Illari, P. and Russo, F. *Causality: Philosophical Theory meets Scientific Practice*, 2014, Oxford University Press, UK, p. 224.

that.²⁰⁸ As Floridi has argued in relation to the philosophy of information, trying to generate timeless philosophy does not advance the field because it is ‘unable to contribute, keep track of, and interact with, the cultural evolution that philosophical reflection has itself helped to bring about’, a statement which could have easily been written about the philosophy of medicine.²⁰⁹ He argues that philosophy’s ‘pulling force of innovation has become necessarily external’ and again these words ring true, with developments in medical technology, surgical techniques, genetics and the emergence and mutation of previously unknown or unrecognised diseases and the challenges of an ageing population all serving to inject the philosophy of medicine with intellectual impetus. None of the changes outside of philosophy, as far as I can see, indicate that we should continue down the road of universal theories of disease. If anything, they reassert the diversity, the confusion, the bluster of a world which cannot be simplified and bent into the confines of stipulation. Without true acknowledgement of the criticisms I have laid out here, philosophy of medicine, Caplan’s ‘intellectual island’ will edge ever closer to disappearing off the horizon, unable to speak for, to, or about pressing issues in modern medicine.²¹⁰

There is, however, one aspect of contemporary philosophy of medicine that is, to my mind, engaging more actively with practice and patients as opposed to conceptual tussles. This is the phenomenology of illness, a topic that I feel deserves a few words now.

²⁰⁸ This is *not* the same as saying I think that disease itself - however you wish to bracket it - is somehow context dependent, or that diseases are constructions of society. Rather it is the way that we understand disease, and indeed what we understand *to be* disease, which is grounded in a here and now or there and then.

²⁰⁹ Floridi, L. 2011, p. 12.

²¹⁰ Caplan, A. 1992, p. 73.

The phenomenology of illness

The branch of philosophy known as phenomenology is instructive here for several reasons.²¹¹ Firstly, it refashions the ‘problem of disease’ away from a concern of demarcation and changes it into a broader question of how philosophy can and ought to respond to illness, and in what ways philosophy might be useful to the sick themselves and those around them. Secondly, it weaves ancient and contemporary thought together in the same framework, using illness to inform longstanding and central philosophical questions. Thirdly, and most importantly here, phenomenologists working on disease do what I have criticised others for not doing: they engage with medicine, with patients and with sickness in a manner that is not only illuminative but also has potentially practical consequences.

Havi Carel, a prominent phenomenologist, makes the claim that illness is a ‘*violent invitation to philosophise*’ (emphasis in original) because of the way it compromises the normal subject-object operation of embodied selfhood and makes us confront our bodily existence, whether we would like to do so or not.²¹² Illness, in this sense an interruption, an uninvited disjuncture, forces us to approach our embodied selves in a new way. This focus on embodiment and being-in-the-world has many benefits. It not only gives us tools and insights to challenge the Cartesian spirit so present in both medical and lay understandings of the body but it also exposes the extensive reach and fault-lines of such a worldview. Furthermore, this work focuses

²¹¹ I do not have the space here for a discussion of what the phenomenological method *is*, or to describe the various intellectual currents within the field. For canonical texts, see: Husserl, E. *Ideas: General Introduction to Pure Phenomenology*, 2012, Routledge, UK; Merleau-Ponty, M. *Phenomenology of Perception*, 2013, Routledge, UK; Satre, J. *Being and Nothingness: The Complete Text*, 1969, Washington Square Press, USA; Heidegger, M. *Being and Time*, 1978, Wiley-Blackwell, USA. For an overview, see Moran, D. *Introduction to Phenomenology*, 1999, Routledge, UK.

²¹² Carel, H. ‘The philosophical role of illness - and how it can teach us to live reflectively’, Article, *The Conversation*, 2016a, <http://theconversation.com/the-philosophical-role-of-illness-and-how-it-can-teach-us-to-live-reflectively-57310> (accessed 22/04/17).

on the experience of disease in a way that other philosophy avoids: it is messy, subjective, narrative, qualitative. But is it also, I believe, edifying. Unlike the high-minded conceptual tussles described in this chapter, phenomenology offers patients a way of approaching their condition that may allow them to achieve ‘well-being within illness’, as well as reminding doctors that the biomedical world they describe to a patient may not be isomorphic with the sufferer’s experience.²¹³

Whilst the 20th century thinkers who loom large over phenomenology - Heidegger, Merleau-Ponty, Husserl - had little specific to say about illness, they bestowed upon later writers a sophisticated method for approaching the problem. It is these thinkers I will briefly examine here, from the work of S. Kay Toombs and Drew Leder through to more recent studies by Havi Carel.²¹⁴ Taken together, their body of work represents a serious challenge to reductionist models of medicine and draws attention to both the transformative and informative nature of disease as an subject of inquiry.

S. Kay Toombs, a philosopher with multiple sclerosis, has written extensively and originally on the phenomenology of illness. Ironically, given the critique provided above, her starting point is that there are essential (Toombs terms them ‘eidetic’) features to the illness experience, not specific to one condition.²¹⁵ These characteristics, which ‘transcend the peculiarities and particularities of different disease states and constitute the meaning of illness-as-lived’, revolve around loss: the loss of certainty, of control, of freedom to act, of the familiar world and of a sense of

²¹³ Carel, H. ‘Can I be ill and happy?’ in *Philosophia*, 2007, Vol. 35, No.2, pp. 95-110.

²¹⁴ These are not the only influential thinkers in this field, but I have chosen to examine them because they have either written the most extensively or present a thesis uniquely salient to this work. For an overview of the literature on this topic, see Carel, H. *Phenomenology of Illness*, 2016b, Oxford University Press, UK, pp. 35-39.

²¹⁵ It should be noted that she later weakened this from ‘essential’ to ‘typical’: Toombs, S. K. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, 1993, Springer, USA.

wholeness.²¹⁶

These aspects of illness are common and universal, she argues, but her intention is not to bracket 'illness' as a category to be delineated or denied in the manner of disease. Rather, she hopes to show how the 'world' of illness and the patient - whose spatial and temporal structure fluctuates - is separate from that of the physician, who deals in the body-as-object and the disease-as-entity, and suggests that a greater understanding of these disparities would pave the way for better care.²¹⁷

Patients and doctors need to work together to find a shared language, recognising that the manner in which one party (those who are ill) experience illness not as a biological dysfunction but as a rupture of their lived body dictates what are and are not appropriate forms of communication.

Bringing prolonged attention to the ways in which disease alters our experience of the world, and to the consequences of these changes, was Toombs' key contribution in my view.²¹⁸ She outlined the ways in which disease is capable of rendering the world a changed place, in which objects with previously unambiguous and benign roles now appear to be obstacles or challenges. Furthermore, she described the alienation that can arise when a patient and a physician talk past each other, one about normal ranges and white blood cell counts, the other about not being able to walk up the hill to their house. Ultimately, it is this that Toombs was trying to make us understand: that serious disease is almost always transformative, and by interpreting that transformation in narrow biomedical terms, we run the risk of witnessing successful communication between doctor and patient break down. Pa-

²¹⁶ Toombs, S. K. 'The meaning of illness: a phenomenological approach to the patient-physician relationship' in *The Journal of Medicine and Philosophy*, 1987, Vol. 12, pp. 228-235.

²¹⁷ I have simplified this account in the interests of brevity - following on from Satre, Toombs actually identifies four layers of illness experience: Toombs, S. K. 'The Temporality of Illness: Four Levels of Experience' in *Theoretical Medicine*, 1990, Vol. 11, pp. 227-241; Toombs, S. K. 1993.

²¹⁸ This insight was not limited to disease, but also applied to disability: Toombs, S. K. 'The lived experience of disability' in *Human Studies*, 1995, Vol. 18, pp. 9-23.

tients and physicians must not let their different experiences of the same body (the body-as-lived and the body-as-analysed) mean that total delineation occurs, and neither finds themselves speaking to the other about the same thing.

Other writers have used phenomenology and personal experience to make broader points about the metaphysical scaffolds that support our world views (or ‘habits of mind’, as some phenomenologists would have it). For example, in his masterful study of embodiment *The Absent Body*, Drew Leder utilises an intense examination of our bodies as experienced (or not) in order to highlight not just what is taken for granted about our every day bodily lives but also to undermine the tendency towards disembodiment which he takes to lie beneath our entire intellectual tradition. He does this by first explicating in detail the way in which our bodies are often removed from consciousness, whether obscured, forgotten, automated or otherwise concealed from our attention. It is difficult, he says, to become aware of a body so often relegated in this manner. ‘Feelings of general neutrality’, he writes, ‘or well-being are typically amorphous, marked neither by definable beginnings and ends nor abrupt transformations’.²¹⁹ A large part of his study focuses on the ways in which this ‘invisibility’ occurs, and the interruption that disease causes to such an arrangement, but the most important contribution he makes, as far as this discussion goes, is his unrelenting assault on the clean division of mind and body, a process of disembodiment he views as ‘an abiding stream in Western intellectual history’.²²⁰

The problem he identifies and criticises is the way in which our medical notions of embodiment are based upon abstractions or, when they are tied to the flesh, upon a mechanistic thematisation of corpses. As he says:

²¹⁹ Leder, D. *The Absent Body*, University of Chicago Press, USA, 1990, p. 72.

²²⁰ *Ibid.*, p. 3

‘We can inspect a dead body in a way we cannot the living. Modern medicine, profoundly Cartesian in spirit, has contrived to use the corpse as a methodological tool and a regulative ideal. Medical education begins with the cadaver, just as the clinical case ends with the pathoanatomical dissection. Death unveils the truths of the inner body and its diseases... Notions of embodiment based upon the corpse can lead to an objectivist, depersonalised medicine. The physician need not attend to the patient’s intentionality when he or she is conceived of as a physiological machine’.²²¹

Though I have covered similar ground myself (see Biomedicine, Chapter I), Leder makes an interesting point which I would like to touch upon. He argues that that a positive feedback loop exists between dualist metaphysics and western society, as experienced on a bodily level.²²² In other words, what began as a theoretical abstraction has become codified into ways of seeing and organising the world, which in turn feeds back into and strengthens our dualistic schematisations of our bodies and disease. ‘We are all to some extent Cartesians’, he writes, ‘either willingly or struggling to get free’.²²³ I think there is something profoundly correct about this, though it can express itself in oblique ways. Patients find, as will be discussed in Chapter IV, that they simply do not have the language to adequately describe what is happening to them. This is because of a failure of categorisation - a prevailing notion that the phenomenological world can be neatly assimilated into the biomedical one. That this assimilation does not happen, or happens in a clumsy, inelegant way, is no surprise, but that does not lessen the negative effects of such a failed integration. What Leder points to - what I am pointing to - is the sense that

²²¹ Ibid., pp. 146-147.

²²² Ibid., p. 152.

²²³ Ibid., p. 108; The extent to which this dualism is internalised and the problems that can arise from it will be discussed in Chapter IV.

our entire system of categorisation is flawed, and that it cannot encompass that which we think it can or should.

Havi Carel, a contemporary philosophy who I reference at several points during this thesis, has written extensively on the phenomenology of illness, covering too broad a range of topics to be effectively summarised here.²²⁴ In place of an overview I would like instead to mention two particular components of her work: her repeated assertion that illness is a fantastically apt subject for philosophers to work on and her attempts to use philosophical tools in a wide variety of circumstances. The questions she asks as a result of this approach are more direct, more personal, more relevant. Can we, for example, be happy within illness? What can philosophy teach us about being sick and can it change our experience of sickness for the better? A person with chronic illness herself, she writes:

‘I have the most pressing and personal interest in understanding the illness experience and in thinking about how to make that experience less lonely, alienated and socially scripted. In the years since I was diagnosed I have navigated my rickety boat of selfhood between the Scylla of medicalisation and objectification of my illness and Charybdis of social pressures to conform to the ideal of ‘the good patient’ or ‘sick role’. When subjected to philosophical analysis, this navigation, both philosophically salient and pragmatically important, can help us understand illness as part of self-hood: it is thus of prime philosophical value’.²²⁵

²²⁴ For example, she extends Toombs’ thoughts about the losses that illness can bring, focusing in particular on the loss of freedom, discusses the ways in which illness can have a benign effect on a person’s wellbeing or at least provoke a surprisingly positive reaction (see also: Kidd, I. 2012, pp. 496-520), expands Fricker’s notion of epistemic injustice (see p. 151) and also provides several in-depth, phenomenological accounts of breathlessness as part of a large, collaborative project called *Life of Breath*.

²²⁵ Carel, H. ‘Living in the Present: Illness, phenomenology, and well-being’ in Jackson, M. (Ed.) *The Routledge History of Disease*, 2016, Routledge, UK, 2016c, p. 582.

What she touches on here is something I wish to echo, albeit less eloquently, throughout this thesis: severe illness is a philosophically fascinating and serious object of inquiry, the grip of which only the luckiest of us are likely to completely escape. It makes us think about ourselves, about our limitations and our strengths, it puts enough strain on our relationships to show them for what they are; it brings us closer to death, whether that entails reflection, contentment, fear or something else; it removes us from the sanitised world we have created and reminds us of our biology, whilst pushing us into the hands of expensive, gleaming pieces of technology. It is transformative, in other words, though the nature of the transformation is unpredictable and idiosyncratic. Disease affects everyone in different ways:

‘The values and desires of ill people can alter. They may slow down or speed up, reconsider their career, or want to spend more time with their family; they might find new meaning in work or as a volunteer, and they may value time and simply living in the present more highly. Goals and ambitions are often updated, taking into account the limitations and opportunities brought about by illness, perhaps becoming more focused on what is still possible. Their world-view may change deeply. They may become depressed, or more religious, or happier. And, of course, they may not change at all’.²²⁶

This transformation, in all its nebulousness, is a worthy topic of philosophical examination, and it is to the credit of phenomenologists that they approach the problem of disease in such a way.

Carel in particular has produced thoughtful work in response to this idea of illness-as-change which tries to ally philosophy with pragmatism, utilising not only the

²²⁶ Carel, H., Kidd, I. J. and Pettigrew, R. ‘Illness as transformative experience’ in *The Lancet*, 2016, Vol. 338, Iss. 10050, p. 1153; it is important to remember that ‘transformation’ in this context is meant literally, without implying particularly positive (or negative) outcomes - as the changes may well be a mix of both, or just push in one direction.

knowledge and insight that philosophy can bring to an individual but the method of philosophising itself. She helped to develop a ‘phenomenological toolkit’ for patients, that might be delivered through one-day workshops, with the aim of improving both patient’s understanding of their own condition (in a philosophical rather than medical sense) and giving them tools with which to develop a ‘thick’ conception of illness.²²⁷ This is a conception in which all aspects of the disease are considered as interconnecting points of impact on a person’s life, where views illness as a gateway to a new way of ‘being in the world’ for the patient, rather than as a disembodied biological dysfunction that is separate to the sufferer (in that it is abstract, depersonalised and talked about in statistical, universal terms).

I stated at the beginning of this brief section that the work of phenomenologists has practical consequences, and I do believe this to be true. I think it could be of great comfort to an individual to come to see their condition not simply as an unwanted, external intrusion into their lives but as something transformative of their way of being and not necessarily in a negative sense. Likewise, I think it could be of great help to a physician to more deeply understand that the world they transpose from textbooks onto their patients is not the same world that the individual in their clinic lives in. But, having stated these positions as I have, does it not seem fairly self-evident that illness is transformative and that doctors should think about things from the perspective of the patient? And, undoubtedly useful as philosophy might be to some individuals in coming to terms with their new position in life, so might self-help books, or running, or listening to Radio 3.

This is where the specificity of phenomenology comes into play, in that philosophers in this discipline have articulated and fleshed out the notion of transformation within illness, tied it to other’s works and generally speaking given the concept

²²⁷ Carel ran some small-scale, pilot versions of these workshops in conjunction with GPs and patients, but never took them further (personal correspondence).

a depth and clarity where it once may have seemed glib.²²⁸ Having accounts of illness like Carel's and Toombs', which peg themselves closely to the patient experience in all its permutations allows us to consider illness in a fuller, more complete manner - it gives us more to chew on, so to speak.

It is also complimentary to much work that has been completed in the sociology of health and illness, and works in tandem with it by providing a philosophical explication of the personal level of meaning and interaction to supplement the social. A good example of this is how Toombs' concepts of the patient's and doctor's separate 'worlds' compliments Mishler's idea of the lifeworld: Toombs provides an experiential account of the broken interactional model that Mishler famously described by analysing doctor-patient transcripts.²²⁹

Phenomenology thus reinforces what sociologists have been arguing for decades: patients' views matter, disease is not best understood as a biological dysfunction, illness alters the functional boundaries of an individual's life. But it also utilises sophisticated philosophical tools to challenge biomedicine, highlight epistemic injustice and to recognise all the ways in which disease is 'world-changing'. Phenomenology sets itself apart from other aspects of philosophy of medicine (and from sociology) by being attentive to disease as it is lived, by being conceptually astute and by offering deep analysis of the breakdowns that occur along common fault lines. Its usefulness is such that I will continue to draw on work done in this tradition at various points throughout this thesis.

²²⁸ Such as L. A. Paul's work on decision making and transformative experiences in Paul, L. A. *Transformative Experience*, 2014, Oxford University Press, UK; I mean by this that it is glib to say that illness transforms - how it does so, in what way and for what reason, now these are the real questions.

²²⁹ Mishler, E. G. *The discourse of medicine. The dialectics of medical interviews*, 1984, Norwood, USA.

Concluding remarks

This chapter has been a critical analysis of the way that, over a number of years, a certain strand of philosophy has approached the problem of disease. I have noted the motivations, both potential and given, for this undertaking and found that the aims of theorists are insufficiently fulfilled by their attempts. What's more, it seems highly likely, as detailed here, that it is not the attempts themselves that fail but the method by which they are assembled in the first place and the rules they must adhere to. Of particular relevance to this thesis is the lack of contribution such theories make to our understanding of contested illnesses. Many of the issues I detailed in the first chapter are at most lightly brushed by the ideas discussed here. But if we are to insert philosophy into these problems (and I think we must), then where to begin?

Focus, certainly: diseases not disease. A continued acknowledgement of the complicated and the inexplicable and the diverse; a tendency to shy away from attempted containment, universalism and essentialism, instead falling more towards individuated experience. A desire too, whether in analysis or description, to imagine other worlds, other ways of being patients, of being doctors, of being bodies, this being in itself the surest method to avoid acceding total epistemic stewardship to medical science, remembering always that we are not simply engaging with a scientific enterprise but with a process inseparably tied up with symbolic meaning. It is this - the production and dissemination of meaning - that philosophy of medicine should be most concerned with, and yet it is a subject on which many remain largely tight-lipped. What do we think, why do we think it, how does it affect our health and can we shift our perceptions to make us feel better? These are more useful questions.

Fundamentally, I think the philosophy of medicine literature around disease frustrates me because of the lack of insight it offers into people's lives. This may be too

lofty an aim to bestow upon what is, really, an intellectual exercise much like many others, but disease appears to me to be a particular topic of inquiry that, more than invites, *demands* serious reflection. It is the imposition of an altered state on a person, for sure, but it is also the meeting place of biology, culture, science, technology and economics. Contested illnesses, to as much of if not greater degree so than other diseases, sit at such junctions, and their study tells us so much more than simply a reductive narrative of personal impairment.

In the next chapter I will look at three writers outside of the philosophy of medicine, (a cultural critic, a historian and a philosopher of science), all of whom in different ways have discussed disease in the broader sense hinted at above. Their work is directly relevant to the topic at hand, as it focuses upon conditions that dwell in the shadowy netherworld between valid and illegitimate illness, but it also serves as a partial rebuke to the subject matter of this chapter. That is because it strives to unpick people's lives and their experiences, and because it thinks that these are the most important questions.

Chapter III - Shorter, Showalter, Hacking

In the previous chapter, I discussed at length the relevance (or lack thereof) that contemporary philosophy of medicine has to contested illness in relation to the central question of this thesis. That question, or rather cluster of questions, being in some strong sense to do with the way we experience illness, both as patients and as healthy bystanders; those question essentially being *what qualifies instinctively as disease and how does it do so? - what do we expect to look at when we look at a sick person? – how do we grade information given to us by our bodies, by professionals and by the people around us? - what are the social and institutional contexts in which our diseases live?*

We may not, indeed, be much closer to answering these concerns, but I have begun to sketch out the foundations of the discussion. Legitimacy, validation, responsibility, biomedicine, embodiment – all these find a place in our language of disease, and in particular of contested disease. By the end of this chapter I will have added a handful more. And although I believe there is little to be usefully gleaned from the disease definition debate in terms of helping us to understand the philosophical underpinnings of contested illnesses, this does not mean that no interesting or relevant scholarly work has been completed recently which can further our comprehension of what is, at its most clear, a muddied subject.

In this chapter, then, I will turn my attention to two historians and a philosopher who in many ways could also be classified as a historian. The former pair, Edward Shorter and Elaine Showalter, have both courted controversy in patient communities with their historical analysis of psychosomatic illnesses, psychiatry and, in the case of Showalter, hysteria specifically. The reasons for this are, I surmise, a combination of form and content. Their theses, though distinct, overlap in many significant ways; they believe that chronic fatigue syndrome, fibromyalgia and many other similar conditions exist on a historical continuum with previous psychosomatic conditions, and that they are for all intents and purposes the current incar-

nation of hysteria. That is to say, of emotional distress finding an outlet subconsciously through physical symptoms, the exact manifestation of which is dependent on prevailing notions of acceptability. This does not sit well with those who believe their illness to be primarily organic and whose identity has come to a certain extent to be formed in opposition to those who say or act as though it isn't. Both writers present this idea in a somewhat forthright manner, which does not endear them to patient communities who feel belittled and patronised. It is, however, notable that whilst they remain controversial figures for many individuals with contested illnesses, they have received minimal criticism from fellow academics.²³⁰

It is my intention to give the ideas presented by Shorter and Showalter a fair reading and to analyse the claims they make, especially relating to subconscious symptom selection (drawn from the so-called 'symptom pool'), cultural transmission of disease and how the changing nature of the doctor-patient relationship and the family have affected patients. The inferences they draw from historical examples are not inconsistent with adequate contemporary patient care and to deny their relevance (as some do) is simply ignorance. Though I do take issue with the tone used on occasion, what I will be most attentive to is their ideas.

The last individual of the three, Ian Hacking, is a philosopher who has written extensively about dynamic nominalism and the relationship between individuals and the categories they are placed (or place themselves) into. His exemplary studies of multiple personality disorder and dissociative fugue are the brightest stars in a constellation of writings around this topic, his contribution to which he has phrased his 'Making Up People' project. His work follows in the long tradition of natural kinds but the ways in which he has adapted nominalist debates into a modern framework of interaction - positioning himself between a Foucauldian structural

²³⁰ For an example of the backlash against Shorter and a description of the reaction to Showalter, see (for Shorter) Scott, D. W. and Scott, L. C. *The Extremely Unfortunate Skull Valley Incident*, 2003, Trafford Publishing, USA and (for Showalter) Larkin, M. 'Elain Showalter: hysteria's historian' in *The Lancet*, 1998, Vol. 351, No. 9116, p. 1638.

analysis and Goffman's closely observed sociology of mental illness – give it resonance for the discussion here. It concerns identity and the structure of thought and memory, and has provoked a fairly vigorous response from other philosophers.

What I believe Hacking has gifted us with is a loose but ingenious framework of looping between individuals and institutions, one which despite his protestations of simplicity and simple-mindedness has grown into a fairly sophisticated tool with which to approach certain topics, especially when used in conjunction with his less appreciated ecological niche concept. To what extent his ideas can be adapted and hold true to specific cases of contested illnesses will be left for the final chapter, though arguably his existing work has already dealt with, to a certain extent, contested illnesses of a sort.

What all three of these writers have in common is the importance they place on viewing the patient in context. A sick person is never just a sick person. They are part of a group of individuals experiencing similar sensations, part of a society that gently and not-so-gently nudges them towards certain patterns of behaviour and explanation and away from others; they become both willing and non-willing, conscious and unconscious agents of their own distress. That this happens is, to some extent, less contentious or problematic than how it happens. How do shady interactions with the vagaries of 'culture' produce specific illness behaviour and beliefs? Is the restructuring of experience that is posited to occur anything close to a consistent process?

That questions like these lie at the heart of the work discussed below is in large part why I have chosen to discuss it in the first place. There would be a great deal missing from our understanding of disease and contested diseases if we were to lean solely on the philosophy of disease literature for analytic support, and so by bringing in these thinkers from other disciplines, I hope to cast more light and shadow on the topic at hand. That is to say, I hope that their words and thoughts will give depth and shape to the lives of the patients I examine in the next chapter,

though I am not uncritical in my use of them.

Shorter

Edward Shorter has been described as a ‘highly critical’ historian of psychosomatic conditions.²³¹ There are four strands of his work that are relevant here: the historical continuity of past psychosomatic conditions with modern illnesses, the subconscious mind’s desire to be respected and to choose ways of expressing its pain that reflect this, the decline in trust between doctor and patient and the increased atomisation and loneliness of postmodern family life. Taken together, these provide a coherent if conservative explanation and analysis of contested illnesses, and one which makes us question the consequences of sympathetic doctors, the role of the media and the whole social matrix of a modern patient.

Historical continuity

Across his two most famous works on the subject, *From Paralysis to Fatigue* and *From the Mind into the Body*, Shorter strongly argues for a total historical continuity between hysteria, railway spine, shellshock, neurasthenia and any number of other ancient appellations for unexplained medical symptoms with conditions we see around us today such as chronic fatigue, golf war syndrome and fibromyalgia.²³² That is not to say that a fibromyalgia patient feels and presents in the same way as a hysteric, just that the root cause is the same. Shorter believes that undulations in

²³¹ The epithet is Hacking’s: Hacking, I. *Rewriting the Soul: Multiple Personality and the Sciences of Memory*, 1998, Second Printing, Princeton University Press, USA, p. 156.

²³² Shorter, E. *From Paralysis to Fatigue: A History of Psychosomatic Illness in the Modern Era*, 1993, The Free Press, USA; Shorter, E. 1994.

the professional structure of medicine and psychiatry, as well as various ripples across the cultural life of the societies in question, lead in some tangible but slippery way to different symptoms being ‘popular’ at different times.²³³ The conditions *have* changed, then, in the sense that the way patients present in clinics changes as you look over the years. However, this metamorphosis of symptomatic profile forms a large part of Shorter’s evidence, for he contends that our body only expresses emotional disquiet in ways which are considered acceptable and explicable in the social and intellectual milieu in which it exists.

Paralysis, then, as an example, ‘was a culturally specific nineteenth century mode of processing extreme emotion’ and is not seen today in as great numbers because it is not as deeply imbedded into our social consciousness as a way of experiencing distress legitimately.²³⁴ This can be observed in the way that, whilst once common among a certain class of young women, paralysis ceases to be seen frequently once the Babinski sign and test became well known: it is difficult to claim you are paralysed when an ‘objective’ test of your reflexes finds them to be working normally. The same could be said for claiming to have a strange object or animal inside you once the power of x-rays became well disseminated or for professing issues with your heart, lungs or sensory organs once these became exceptionally easy to monitor and investigate with the tools and feelers of modern medicine. The argument goes that once paralysis (or whatever) becomes somehow discredited or illegitimate, the body will find another, more acceptable or, at least, less disprovable way of somatising.

²³³ I put ‘popular’ inside quotation marks because although Shorter frequently employs this kind of adjective, along with ‘fashionable’, ‘trendy’ and the like, I find that the connotations of conscious decision-making and glibness associated with these words detract from their relevance as descriptors. I am not the only one to think Shorter’s loose relationship with language can undermine his scholarship - Fitzhugh Mullan makes a similar point in Mullan, F. ‘Revolt of the Postmodern Patient’ in *The New York Times*, 02/02/1986.

²³⁴ Shorter, E. 1993, p. 114.

Shorter is clearly very much of the opinion that whilst there is something permanent about ‘organic’ conditions, or diseases with an identifiable physical lesion, psychosomatic illnesses, both then and now, are permanent only in their cause and vary wildly in their manifestation. That this cause itself is vague – a sort of maladjustment, a realised or unrealised discontent – only serves to make them more difficult to identify and analyse. The specific symbolism of this unhappiness may migrate from one vector to another; the nineteenth century woman unknowingly reacting against the stupefying passivity that defined her femininity is different from the man returning from the trenches was unable to reconcile his civilised existence with the horror he witnessed, but both are uniform in the sense that they are unhappy in ways they do not comprehend. What Shorter says is that to these archetypes we can add the career-driven yuppies of the 80s who suddenly found themselves unimaginably tired and lonely divorcees wrestling with an unfulfilling and tedious existence who begin to ache all over.²³⁵ Their cultural and personal situation is different and thus the symptoms they experience are not the same, but the heart of the problem remains that their bodies are expressing sadness without informing their minds. Or rather, that this is their method of informing them.

What is evident from the outset is that Shorter is keen to dispel concerns of insensitivity and is worried about being misunderstood. On the very first page of *From Paralysis to Fatigue* he states:

‘It should be emphasised...that from the patient’s viewpoint psychosomatic problems qualify as genuine diseases. There is nothing imaginary or simulated about the patient’s perception of his or her illness. Although the symptom may be psychogenic, the pain or grinding fatigue is very real’.²³⁶

²³⁵ Shorter notes that a diagnosis of hysteria or similar is as likely to emerge from a life of leisure as it is from extreme hardship: Shorter, E. 1994, p. 66.

²³⁶ Shorter, E. 1993, p. ix.

His lip-service to the reality of the pain is undermined however, by repeatedly implying throughout his work that psychogenic mechanisms are ontologically less valid than biological ones. By arguing that, in one case, organic disease, both symptoms and internal distress are ‘real’, whilst maintaining that only half of this duality is present in a somatiser, he drives a wedge between them that preferences the organic illness. At no point does he adequately examine or explain why the metaphysical basis for one form of reality, (pain caused by an anatomically observable dysfunction), is placed above another, (pain caused by some other, harder to identify mechanism, as with psychogenesis).

It may be possible to infer clinically useful reasons why symptoms and symptomatic experience, that is, the difference between the fact that the muscles in my arm ache and the pain it causes me, should be separated, but on the whole Shorter does not go down this route. To him, physical diseases are the permanent or semi-permanent bedfellows of mankind. They are constant throughout history.²³⁷ Psychosomatic conditions, on the other hand, are products of a time and place, morally charged in a way that other diseases aren’t, and heavily, heavily influenced by outside factors.²³⁸

What are these outside factors? Shorter speaks often of the ‘symptom pool’. By this he means that at any given time and place there are acceptable and unacceptable ways of being ill.

²³⁷ To me this seems to be a contentious claim. It does not seem unreasonable to argue that to a (perhaps lesser) degree what Shorter considers ‘organic’ disease is also greatly affected by its social surroundings. Plenty of conditions require specific environments in order to flourish and come and go historically - for example waterborne diseases in heavily populated areas. Furthermore, some diseases simply *are* different: to take a common example, the diabetes patient of today would be unrecognisable to doctors even in the mid-20th century (see Polonsky, K. S. ‘The Past 200 Years in Diabetes’ in *The New England Journal of Medicine*, 2012, Vol. 367, pp. 1332-1340).

²³⁸ It should be noted he is talking about symptomatic presentation here, with a consistent underlying mechanism. As he writes, ‘[the] tendency to convert unhappiness into physical symptoms is probably universal in the human species’, Shorter, E. 1994, p. 88.

The symptom pool

To display acceptable symptoms, as used by Shorter, is to feel sick in a way that absolves moral responsibility for your symptoms, but also in a way that accords with the expectations and prevailing scientific notions of biological illness behaviour:

‘The unconscious mind, just like the conscious, is influenced by surrounding culture, which has models of what it considers to be legitimate and illegitimate symptoms. Legitimate symptoms are ascribed to an underlying organic disease for which the patient could not possibly be blamed. Illegitimate ones, by contrast, may be thought due to playacting or silliness. By defining certain symptoms as illegitimate, a culture strongly encourages patients not to develop them or risk being thought ‘undeserving’ individuals with no real medical problems. Accordingly there is a great pressure on the unconscious mind to produce only legitimate symptoms...the unconscious mind desires to be taken seriously and not be ridiculed’.²³⁹

There are then three identifiable parts to what Shorter would consider a legitimate symptom. It must accord with overriding ideas of validity, that is to say that for a symptom to be acceptable it should relate to some current theory or other of the body that is widely acknowledged to be correct. This idea can then be used to explain how symptoms have changed over time in tandem with movements in general aetiological frameworks of disease. The second part is intertwined with the first, that the symptoms displayed must work to absolve the patient of moral responsibility for their illness. This is usually most successfully achieved by mimicking that which has the most credence and commands the most respect, and in this cultural

²³⁹ Ibid., 1993, p. x.

context that means established, observable, quantifiable, organic disease.²⁴⁰ The third part of this idea, by implication, is that there exists some powerful mechanism of cultural transference which imbues in the popular mind a list of acceptable and non-acceptable means of being ill, which in times of crisis is used to communicate emotional dysfunction in a painful psychical language.

Shorter suggests two further clarifications of this point. Firstly, he puts emphasis on the doctor-patient relationship as a means by which sick individuals are able to gauge what is expected of their bodies according to the ideas of the day. He does not place this inside a simplistic framework of suggestion, Charcot-style, but provides a more sophisticated account of an important dynamic which changes over time from one of idolatry and patriarchal hierarchy to a process based more on individualistic market models of healthcare, growing mistrust of authority and a preference for pharmaceuticals.

Secondly, he argues that patients are aware or become aware of the 'trends' in symptomatic presentation which are most in harmony with contemporary explanations of illness. How this occurs has likewise developed over time, from the popular culture of the nineteenth century, be it novels, the theatre or forms of spa tourism, to the sensationalist mass media and day-time talkshows of the 1990s, all the while buffeted by the ever-present influences of friends, family and word-of-mouth. In his words, the 'two actors in this psychodrama...are, and have always been, doctors and patients...Doctors' notions of what constitutes 'genuine' organicity may alter, perhaps as a result of increased scientific knowledge or new cultural preconceptions. Although patients' notions of disease tend to follow doctors' ideas...patients may also change their notions of the legitimacy of symptoms that

²⁴⁰ It is not impossible to imagine, however, an alternate historical or contemporary scenario in which the parameters of respectability were different, and therefore a different mode of illness was 'aped'. Presumably, Shorter would contend that his theory would still hold true in this circumstance, if he were to admit the usefulness of conceiving such a universe.

have little to do with medicine'.²⁴¹ To give this idea a little more flesh, let us see how it operates through one of Shorter's examples, reflex theory, which was influential in the second half of the nineteenth century.

In the most basic sense, this was the idea that any organ in the body could, by means of a 'reflex arc' transmitted through the nervous system of the spine, affect at a distance some other organ or bodily function. In particular, the uterus was seen as a troublesome piece of anatomy (when is it not?), and was the site of growing medical meddling with female reproductive organs. It was thought that, as every internal item was connected dynamically with every other, and as the uterus was believed to be among the most influential of all parts of the female body, it made sense that in some form or other it would be sending nefarious signals to all the things it could reach.

Targeting the uterus as the source of disparate symptoms was not the only method of applying this theory to treatment. Connections between distant body parts were constantly being drawn and redrawn, and remedies included pulling on the tongue in order to galvanise the heart, 'propping up' organs through surgery that were said to have fallen out of place and thus caused instability in the nervous system and reflexively generated hysteria, treating breasts to cure a painful womb and cauterising nasal mucosa to influence 'everything imaginable'.²⁴²

The immediate result of this theoretical backdrop, according to Shorter, was that patients, mainly women, became fixated on certain areas of the body which are in fact impossible to experience specifically, such as the uterus.²⁴³ Thus, what was vague pain, tiredness or otherwise dissipated and ambiguous distress became fun-

²⁴¹ Shorter, E. 1993, pp. x-xi.

²⁴² *Ibid.*, 1993, p. 47.

²⁴³ That is to say, you can certainly experience pain coming from the vicinity, but it is not an organ which you can identify from others around it in the way you could, say, with the lungs or heart.

nelled through this analysis into a coherent and centred dysfunction. Though reflex theory and the medical movement it played an integral part in is complicated and multifaceted, Shorter demonstrates quite succinctly how a combination of factors and pressures collide under one banner to provide a complete and convenient explanation of disease, which in turn affects treatment and presentation:

‘For patients it provided a mooring of certainty in the face of the body’s bewildering signals: it was just those pesky pelvic reflexes again. For doctors reflexes provided a general explanation of how disease in one part of the body affected the other parts: nervous signals from any other irritated organ could travel up and down the spinal cord to any other target organ in the body. In women, the uterus and ovaries were thought the organs most susceptible to irritation, thus the organs that drove forward disease processes elsewhere. But reflexes could also spread to the brain, offering explanations of nervous and psychiatric symptoms in men and women generally, but particularly in women because of the permanent state of irritability of the female pelvis’.²⁴⁴

The exact nature of the mechanism whereby culture engenders symptoms, with its changeable weighting over time between doctors, science, other patients and popular media is sometimes difficult to pin down, in a manner that raises for me several problems with Shorter’s approach. I will return to this topic later.

The doctor-patient relationship

So, from historical continuity and the symptom pool, we move now to what I consider the third important strand of Shorter’s thinking, the doctor-patient relationship and the loss of medical authority. He has stated that ‘the history of psychoso-

²⁴⁴ Ibid., 1993, p. 45.

matic illness is one of ever-changing steps in a pas de deux between doctor and patient' and his analysis of the evolving nature of this dance provides some insight into the occasionally antagonistic and counter-productive dynamic that can be witnessed between modern-day sufferers of contested diseases and their various physicians.²⁴⁵

Historically, he identifies and delineates three loose but clear phases in the development of the doctor patient relationship.²⁴⁶ The first, *traditional*, refers to the age before the rise of the doctor as a cultural symbol of trust and healing. Roughly speaking, this means pre-1850, and can be defined by a distrustful and dismissive attitude amongst patients, who for the most part view medicine (accurately) as failing to provide much in the way of diagnostic accuracy or therapeutic efficacy. Following this we entered a period termed by Shorter as *modern*, wherein the doctor became a powerful, respected figure, able to diagnose and explain but in many cases still without the ability to cure with consistency. After the Second World War and just as we entered the age of miraculous medicine, he believes we transitioned to a *post-modern* doctor-patient relationship. This represents a return to a period of cynicism about mainstream medicine, characterised by doctor-shopping, an enormous boom in alternative therapies, increased litigious agitation, the growth of patient communication and networks, the proliferation of new, non-medically sanctioned explanations for illness and the expansion, entrenchment and reduced treatability of psychosomatic conditions. To draw the distinction sharply, until the 1960s, 'near veneration of the doctor was the rule, the demigod in white whose patients would willingly sacrifice their ovaries to suit his theories', whereas following this point 'mistrust of the doctor and refusal to accept his or her reassurance' became the defining feature of doctor-patient interactions in relation to somatisa-

²⁴⁵ Ibid., 1993, p. xi.

²⁴⁶ This sketch is based largely on Shorter, E. *Bedside Manners: The Troubled History of Doctors and Patients*, 1986, Penguin Books, UK.

tion.²⁴⁷

What is of relevance to our discussion here is the thesis that Shorter advances regarding the complex relationship between psychogenic conditions, trust in doctors, placebos and the general therapeutic environment of the contemporary world. His basic idea is that over the time-span of the *modern* period, a number of psychogenic complaints, which are the central loci of his historical focus, began in many cases to be treated quite effectively. This is due to a combination of informal psychotherapy within the consultation itself, which was conducted over a lengthy period of time and incorporated many elements, and a wide range of placebo therapies. Mostly harmless, these suggested cures were often entered into wholeheartedly by patients not only hoping to get better but fully believing that they would do.²⁴⁸ This is the key, according to Shorter, for understanding why in some cases they did indeed improve: because they felt listened to and respected by a professional, who in turn possessed significant authority and standing, and who was able to explicate their symptoms in cogent, scientific terms (be it spinal irritation, reflex theory, neurasthenia or whatever) which in turn came hand in hand with a treatment programme. By some intuitive though mysterious internal mechanism, this benevolent network of suggestion was able to save a great deal of people a great deal of pain.

Things change, however, when post-modern patients appear. A decline in the idea of the doctor as a lionised figure is the result of both push- and pull-factors. On one side, doctors became more and more the agents of scientific fields; immunology, biochemistry and pharmacology were placed above patient and family history and the amount of time spent talking and listening to patient declined as the number of diagnostic tests available increased exponentially. In fact, instances of ‘bed-

²⁴⁷ Shorter, E. 1993, p. 299.

²⁴⁸ The biggest exception to this is the large number of unnecessary surgeries that were performed.

side' medicine became anachronisms, eventually disappearing altogether, as doctors' spaces became more and more centralised and their time with patients more and more limited. The image of illness and methods of treatment that were increasingly offered to medical students at this time are those which were described at length in Chapter I. They were given 'a picture of disease that ignores the mind'.²⁴⁹

On the other side of these trends are developments among patients themselves in the 20th century. The archetype here is an individualist consumer, who has done their own research, has self-diagnosed, is sure of what they want and is unwilling to accept anything different from their medical practitioner, who finds themselves transformed into a gateway to prescriptions and little else.²⁵⁰ This is nothing if not a caricature, but it aptly demonstrates medicine's prejudices and fears around this period. Lying under the surface is a sense that something had gone awry with both the way doctors talk to their patients and the way that patients have come to view their doctors. Shorter certainly takes this stance, and argues that it has had direct ramifications for the way in which psychosomatic conditions are treated (or, as the case may be, not treated).

What these changes have meant is that big chunks of the positive suggestive matrix established in the modern period were eroded, and replaced by systems of care both less effective and more harmful. The biggest aspect of this is pharmacology:

'The problem today is not that patients don't believe in their doctors' scientific qualities. They do: but that scientific status centers almost exclusively on drugs.

²⁴⁹ Shorter, E. 1986, p. 185.

²⁵⁰ This transition in the meaning of the 'patient' from passive receiver of planned, paternal care to active agent in possession choice happened in the UK and elsewhere from the mid to late 20th century: Mold, A. 'Patient Groups and the Construction of the Patient-Consumer in Britain: An Historical Overview' in *The Journal of Social Policy*, 2010, Vol. 39, No. 4, pp. 505-521 and Mold, A. 'Making British patients into consumers' in *The Lancet*, 2015, Vol. 385, No. 9975, pp. 1286-1287.

The torrent of effective drugs since the 1940s has given medicine a gleaming, high-tech allure. Patients of today go to the doctor because they must go through him to get the drugs that are truly powerful'.²⁵¹

There is a further element to this. Yes, in the place of spa treatments, patients want specific, targeted drug treatments that mirror approaches to organic disease. But what is also different is the necessary uncertainty that accompanies such therapy. Trial and error tactics with different medications do little to instil the requisite faith in patients that what they are taking will be effective, perhaps summed up by that familiar and formulaic sentence 'we will try you on X, and, if that doesn't work then we'll give you a course of Y'.²⁵² Without faith, however naïve, the placebo effect ceases to operate.

Shorter adds to this the encroachment of the media into terrain once the sole dominion of medicine. Whereas, in the years of the modern period, medical authority would be largely accepted in areas pertaining to medicine, now we witness a situation where alternate sources of information, sensationalism and epistemic structures more favourable to patient prejudices jostle for space alongside scientific opinion. As Shorter puts it, 'what is different...is that the authority of the mass media has started to take precedence over what was once called medical authority. The dominant medical paradigms of our own time fall unheeded in the babble of media interviews of physician-enthusiasts and wrenching accounts of patients' suffering'.²⁵³

What we are left with then, is a fairly grim view of the situation. Patients who would perhaps have been helped in the past are now at the mercy of their conditions thanks to changes in their expectations and an alienating, dehumanising

²⁵¹ Ibid., p. 92.

²⁵² Known by medics as 'empiric therapy'.

²⁵³ Shorter, E. 1993, p. 314.

medical experience. Doctors, as willing to assist as ever, have less time and more of the wrong tools to help such individuals. There is a dark irony in Shorter's thought here: it is just at the point when medicine comes true on its promises and begins to provide us with genuinely widespread, effective responses to disease that we turn back to cynicism and mistrust.

But while he has provided a fairly credible account of trends within the doctor-patient relationship, there is still much that is unexplained or underdetermined.

He places too much emphasis on the effectiveness of historical treatments of psychosomatic illness. Many, many 'cures' were just as unable to make people feel better as modern treatments, and some, such as unneeded surgeries, institutionalisation and lengthy rest cures, had significantly worse side-effects than current drug courses. Though Shorter himself details the worse therapeutic excesses listed above, he is unable to convincingly reconcile this with his idea of a time when doctors were far more trusted and therefore possessing both more power of placebo and, to some degree, humanity.

His excavation of the 20th century patient is also incomplete. There is little space given to the monetisation of medical systems from the 1950s onwards, the increased education levels of the populace, the growth of 'rights' culture, scandals such as that of the thalidomide babies or, indeed, any number of other factors that could be brought into play to help further explain and analyse this breakdown in trust, which Shorter treats as an unambiguously negative development. The basic facts of this breakdown also remain shakily justified: is it really true that modern doctor patient interactions are characterised by a business-like determination on the part of patients and a cold indifference to pastoral medicine by doctors? I think the likelihood is that this is a highly exaggerated account of what are real trends. The criticisms just listed notwithstanding, Shorter does provide one final framework through which to understand contested illnesses, making explicit reference to chronic fatigue and bringing his work closer to the 21st century. It is on to this, the

fourth strand, that we now move.

The postmodern patient

After identifying and breaking down the other aspects of his thesis, starting with the historical continuity of psychosomatic disease - the sense that 'people have always possessed some kind of implicit model for analysing their internal sensations, and the quantity and nature of sensation have probably been historically changeless', the notion of a 'symptom pool' and the three-phase gestation of the doctor-patient relationship, Shorter provides us with one further tool with which to dissect the conditions that have made up most of his life's work.²⁵⁴ He suggests that trends at the end of the last century acted to loosen up traditional social structures and cast individuals adrift on a sea of uncertainty and bodily obsession:

'At the cultural level, these new patterns come from a distinctively 'postmodern' disaffiliation with family life. If the psychosomatic problems of the nineteenth century resulted from an excess of intimacy in the familial psychodrama, those of the late twentieth century have been the result of the opposite phenomenon: a splintering of close personal ties and a lack of intimacy. These changes of the late twentieth century have had the effect of making people more sensitive to bodily signals than ever before and more willing to shift the attribution of their plight from internal demons to external toxins'.²⁵⁵

The argument he is making here is that in the second half of the 20th century we, in Western societies, transitioned from a view of the family as a unit worthy of ultimate commitment to a milieu in which the 'desire for self-actualisation' takes

²⁵⁴ Ibid., p. 51.

²⁵⁵ Ibid., p. 295.

precedence.²⁵⁶ This is symbolically represented by the salience of ‘the relationship’ (and the willingness to ‘shop around’ for the best one), at the expense of marriage. Consequences from this shift included a significant decrease in multi-generational cohabitation to the point of near-extinction and a marked increase in people either living alone or with just one partner.²⁵⁷

Shorter intimately connects this ‘decline’ in the traditional family unit with two processes, each of which contribute to an increase in psychosomatic behaviour and fixed illness belief. The first of these is the removal of the checks and balances that others in close proximity provide, something he terms ‘feedback loops’, an appellation I will avoid as it might cause confusion with my later discussion of Hacking’s feedback loops, which are different. What Shorter means by these checks and balances are the normal social dynamics that regulate and reassure us about our health, most often provided by others in our immediate environment. When you remove the partner and the grandparent who would ordinarily serve as a sounding board for health worries and complaints, an individual is left to come to a conclusion by themselves or on the internet. Therein lies the danger, says Shorter, for in this individualised, unregulated space obsessive behaviour related to bodily signals develops, not helped by a reliance on mass media or patient groups for further information. Where once there would have been concern but rebuttal, there is now exaggeration and scaremongering.

The second process that Shorter identifies is loneliness. People are now single for longer than before, spend more time living on their own and the elderly in particular are more likely to be socially isolated. This loneliness can breed a discontent that feeds directly into the worries presented above, that of an individual left to gauge their own physical state without the appropriate tools to do so, compounded

²⁵⁶ Ibid., p. 320.

²⁵⁷ Though interestingly, this trend has reversed somewhat in the last decade largely due to economic pressures on housing.

by the fact that unhappiness and somatisation have so often gone hand in hand.

Discussion

His work is, of course, already somewhat out of date. The enormous influence that the internet has had over all of our lives has equally had a large impact on patients. The way they communicate, the sources from which they gather and disseminate information, the very language in which they structure their experiences - all have become both more universal (and thus homogenous) and more rapid. It is difficult to gage accurately the ways in which a truly connected world has changed the dynamics of diseases such as those under consideration here.²⁵⁸

However, Shorter provides us with much more than an antiquated theory. The historical aspect of his work and the ways in which he brings to bear many different factors do provide an answer to the question he sets out to respond to, namely why is it that psychosomatic conditions seem so fluid in their presentation over time and what is it about our current age that would appear so conducive to their proliferation as notoriously difficult, often untreatable entities?²⁵⁹ In fact, with the exception of the internet, most of his ideas can be applied to modern case studies with a little extension here and there but no real issue. He has provided us with a sophisticated template for understanding certain conditions, one which retains relevance as we move through the first quarter of the 21st century.

²⁵⁸ That being said, the evidence does suggest that in some cases these changes have had positive ramifications for doctor patient relations: Iverson, S. A., Howard, K. B. and Penney, B. K. 'Impact of internet use on health-related behaviours and the patient-physician relationship: a survey-based study and review' in *The Journal of the American Osteopathic Association*, 2008, Vol. 108, No. 12, pp. 699-711 and Tan, S. S. and Gonnawardene, N. 'Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review' in *The Journal of Medical Internet Research*, 2017, Vol. 19, No. 1, e9, DOI: 10.2196/jmir.5729.

²⁵⁹ Note: 'an' answer not 'the' answer.

At the beginning of this section, I borrowed Hacking's words and described Shorter as a 'highly critical' theorist. He is precisely that. I am not in the least bit surprised that his work has angered patients of one stripe or another. Though his tone can be sneering and condescending and he oscillates between high scholarship and polemic, this is not the most pressing issue. What is of more concern is his lack of interest in getting underneath the skin of patients and asking why they behave in the ways that they do, especially in relation to rejecting psychological causes. He recognises the problem, and forensically tracks the various ways that this pattern plays out in the 20th century: the refusal of psychiatric help, the demands for medication, the way that a fixed belief in organicity repeats itself over and over in myriad circumstances. What he fails to do is to provide an adequate framework for understanding this process, beyond basic notions of personal responsibility and stigma. The effect of this theoretical sloppiness, especially in light of the thorough approach he takes to other aspects of this work, is to reinforce the notion that these patients are not worthy of the same respect as other sick people, that they are simply being unreasonable, that they are overly pliable pawns of their own imaginations and a solicitous but misguided media.

A better grasp on the metaphysical conceptions of the patient - how do they see themselves and their condition? - what causes them to, apparently so consistently and without thought, latch on to biological explanations and reject holistic approaches? - would allow a more detailed and nuanced attempt at uncovering the exact mechanism of cultural suggestion that Shorter hangs many of his ideas on. Indeed, the experience of contested disease teaches us that whilst patients' relationships with medical authority have changed, their clamour for the legitimacy it brings has not lessened. In fact, it is not so much that patients' have lost faith in doctors or in medical science, it is that their conditions fall outside of the parameters of biomedicine. If there was a true and absolute loss of medical authority, then the alternate aetiological models proposed would not latch on so enthusiastically.

cally to biochemical explanations. The breakdown in trust that is often seen between doctors and patients in this situation is of a more convoluted manner than simply a case of behavioural changes on the patient side and a growing indifference to holistic care on the other; both groups still operate more or less within the same framework, and when conditions emerge that do not fit, the urge of patients is not towards a rejection of medical authority but towards whatever assimilation they can achieve.

Another unresolved tension in this work is the relationship between the 'symptom pool' and patients' subjective feelings. How exactly do trends in scientific understanding, popular culture and the doctor-patient relationship translate into people's everyday experience of their bodies? Put together, Shorter describes these factors as forming the 'climate of suggestion'. The exact importance of one or the other at any given time will vary, and at certain points one aspect of this triad will take precedence.

For example, he states that the introduction of the Babinski test and the use of ophthalmic diplosopes strongly discouraged the subconscious production of paralysis and achromatopsia; as these conditions became liable to being 'disproved', the body sought new and more difficult to expose forms of organic mimicry. For this to be true, in the strictest sense, a fairly extraordinary level of medical and scientific literacy would be required from the population at large. Evidence that might suggest otherwise is lacking, and it unreasonable to believe that the proliferation of relatively niche scientific ideas and technology occurs both

quickly and with regularity.²⁶⁰

As well as this, his specific ideas about the role of suggestion and symptomatic transference from doctors can at times be vague. Whilst he is well versed in the history of this, suggesting for example that ‘the story of Charcot demonstrates the enormous capacity of doctors to frame and shape symptoms which their patients then experience’, he is less clear about how this operates under the modern climate of distrust and rejection of medical authority.²⁶¹ Perhaps we should understand, by implication, that Shorter believes that in modern circumstances the role of the doctor to mould and influence a patient’s symptoms is much reduced.

Alongside the above is his claims about the media and popular culture. Sympathetic or exaggerated coverage of a disease, along with a vague description of symptoms, gives individuals what they have been looking for: a box with a scientific name in which to place their body’s haywire attempts to communicate with them. They now have a research object with its own distinctive traits, something to bring with them when they visit their doctor, some loose form of closure. And, if they do not see the original article or TV show, perhaps a friend or family member did. The net for such concepts is cast wide in a media-saturated society. This sounds like a fairly neat explanation, but again the question is the same: what exactly is the mechanism and why is it so apparently effective? Are these individuals such unthinking and alike agents that their digestion of and response to media reports is so simple-minded? As we shall see in the final chapter, the experience of patients on

²⁶⁰ Although there are issues with using science literacy surveys, they consistently present an image of populations that either misunderstand or are ignorant of fairly basic scientific concepts. A relatively recent survey in America, aiming to discover how much effect a college education had on science literacy, concluded ‘It appears that high school education and students’ exposure to media and popular culture convey a basic knowledge of science, although it is piecemeal and barely adequate’, see Impey, C., Buxner, S., Antonellis, J., Johnson, E. and King, C. ‘A Twenty-Year Survey of Science Literacy Among College Undergraduates’ in *The Journal of College Science Teaching*, 2011, Vol. 40, No. 4, p. 37.

²⁶¹ Shorter, E. 1993, p. 166.

the ground is far, far more complex than Shorter's theory allows for.

Showalter

There is a significant amount of overlap between Edward Shorter and Elaine Showalter's work, so this section will be reasonably brief as I only intend to discuss elements of her research which challenge or expand his ideas. Like him, she believes that many contentious conditions that populate the modern medical exist on a historical continuity with the unhappy women of the Salpêtrière.²⁶² And, like him, she believes that medical authority has been eroded to the point of dysfunction and that various public institutions contribute to the creation and perpetuation of illness. However, she is not just a medical historian but also a literary critic, and her analysis barely takes a step in any direction without recourse to language and narrative. A point she powerfully and repeatedly makes is that words and stories shepherd us through our experiences, making sense of them whilst simultaneously *making them make sense* by smoothing rough edges and incongruities into well worn, recognised archetypes. As she says, 'literature spreads hysteria, but it can also help us understand it'.²⁶³

Her work in this area is more refined than Shorter's, and presents us with a few answers to the questions I posed immediately above. From her approach we can see more clearly how a symptom pool might come to be assembled and disseminated, and what cultural conditions might contribute to what she has, somewhat hyperbolically, termed 'contemporary hysterical epidemics'. She also claims that specific aspects of modern culture mean that 'hysteria' is more 'contagious' and spreads

²⁶² 'Hysteria has not died. It has simply been relabelled for a new era' - Showalter, E. 1997, p. 4 – an opinion about which Hacking says 'Showalter is...profoundly right in saying hysteria is not dead' in Hacking, I. 2002, p. 89.

²⁶³ Shorter, E. 1997, p. 99.

more rapidly than at any time in the past.

Showalter's hysteria

There are, she claims, three ingredients necessary for a modern incarnation of hysteria to take shape and proliferate.²⁶⁴ These are: sympathetic and involved physicians and enthusiasts, disaffected and isolated patients, and a surrounding cultural environment that is conducive to spreading and maintaining false illness beliefs. The first step is for a doctor, scientist or some other person in a position of authority to define, name and publicise a new disorder. This acts as a catalyst for patients looking for a diagnostic label and for some explanation as to what they are feeling. 'The most influential doctors', she writes, 'are...theorists who offer a unified field theory of a vague syndrome, providing a clear and coherent explanation for its many confusing symptoms'.²⁶⁵ As doctors 'recruit' more patients to their diagnosis, so it is that news of the disease is spread through increased press attention. Eventually, through film and television, novels and plays, self-help books and BBQs with your neighbours, the modes of expressing one particular condition or another become familiar - symptoms and stories congeal and solidify, then appear to provide evidence by their very consistency. All of this takes place against a social background which may be more or less disposed to a certain illness at any specific time. According to Showalter, the 1990s in America represented a particularly fertile soil in which for hysteria to grow: technological advances in telecommunications, the birth of the internet, an increasingly pervasive, increasingly confessional mass media - all these intersect with the 'more generalised paranoias, religious revivals, and

²⁶⁴ Sketch largely taken from *Ibid.*, 1997, pp. 17-18.

²⁶⁵ *Ibid.*, 1997, p. 17.

conspiracy theories that have always characterised American life'.²⁶⁶

Although her appraisal is not without mistakes - most glaringly adopting a one-size-fits-all approach to what are quite clearly different phenomena (she conflates the causal origins of chronic fatigue syndrome, satanic ritual abuse, multiple personality syndrome and alien abduction almost unthinkingly, for example) - she does make some genuinely interesting points about how the process of cultural transference of symptoms might occur.²⁶⁷ What is most innovative about her characterisation of this mechanism is the emphasis she places on literary devices being played out in real life. As she says:

'Above all, hysteria tells a story, and specialists in understanding and interpreting stories know ways to read it. As hysteria has moved from the clinic to the library, from the case study to the novel, from bodies to books, from page to stage and screen, it has developed its own prototypes, archetypes and plots. Many of these motifs are adapted from myth, popular culture, folklore, media reports, and literature'.²⁶⁸

What this leads to, she suggests, is a remarkable convergence of both form and content. Individuals begin to experience their symptoms in the same way and talk about it using the same terminology. Interestingly, she also claims that this symmetry extends to developments in the disease; if the condition changes in some form, then the changes experienced are likely to be consistent among patients as they react subconsciously to alterations in their socio-medical environment. As stories of

²⁶⁶ Ibid., 1997, p. 5.

²⁶⁷ A criticism Simon Wessely echoes: Larkin, M. 1998. I would agree with Perring when he says, in response to Showalter's sensationalism and generalisation, that we should instead follow 'the humdrum option of taking the middle way, going case by case, and being cautious' in Perring, C. 'Review - Hystories' in *Metapsychology*, 1997, Vol. 1, No. 27.

²⁶⁸ Showalter, E. 1997, p. 6.

illness are told and retold, they become concurrently more well-known, more similar and more legitimate by their repetition. 'Patients learn about diseases from the media', she writes, 'unconsciously develop the symptoms, and then attract media attention in an endless cycle. The human imagination is not infinite, and we are all bombarded by these plot lines every day. Inevitably, we live out the social stories of our time'.²⁶⁹

But there is a further aspect to this. It is not simply the case that these templates always develop organically or in a linear fashion. On occasion they appear entirely deliberate, created and disseminated by professionals, self-help authors, horoscope writers and patient groups themselves. I do not mean that a group of individuals set out to 'create' a disease, but rather that their actions are focused around the things which spread narrative information about a condition, rather than this being an unintended side effect of some other process. And thus it is that disorders become personalised into prototypes, vague enough to apply to a wide number of cases, specific enough to contain heuristic qualities for readers, viewers and listeners, which they use to solidify their conceptual understanding of the disease.

To show how these various ideas of cultural support and prototype development interact in an actual disorder, I will borrow Showalter's convincing example of anorexia from the mid-20th century onwards.²⁷⁰ Firstly, the surrounding culture in America at that time was broadly sympathetic to the development of such a condition. Aesthetic demands were placed on the female body like never before, an ideal body type projected across magazine stalls, billboards and cinema screens. Adolescent girls were the vulnerable group most likely to be affected by these new obsessions with thinness, weight-loss, beauty and exercise. They ate up the popular culture of the 1960s onwards and internalised the messages about beauty and happiness it conveyed. Then, an articulate and well-known authority figure, Hilde

²⁶⁹ Ibid., 1997, p. 6.

²⁷⁰ Ibid., 1997, pp. 20-21.

Bruch, provided a coherent theoretical framework for anorexia, and through two widely read books popularised her ideas and inserted the basic ‘facts’ about the illness into the public consciousness. Not only this, but these works outlined what was to become the prototypes of the disease - the quiet, obedient sorts of girls it affected most, the identification of mother-daughter dynamic as especially important, the rejection of natural sexual maturation as a symbolic cause. This information was then replicated in one form or another and circulated through news reports, teen magazines, TV, movies and best-selling novels. After this came celebrity confessions and anorexia autobiographies, as well as a large amount of young adult fiction which tended to vary little in basic plot. Alongside these developments arrived the ‘social life’ of anorexia, the group counselling sessions, peer-support groups and its assimilation into parts of the feminist movement. It is certainly a compelling picture.²⁷¹

What I think we can take away from this, in conjunction with Shorter's work, is the multitude of obvious and subtle ways that our cultural surroundings structure how we interpret reality. It seems convincing to me that over time an individual might take on board certain pieces of narrative information about a disease and generate from that a series of subconscious expectations and ways of ordering experience that accords with what they have seen, heard or read. This is, I suspect, especially true if the condition is widely known and well publicised. To reach for an obvious example, the narrative connotations of cancer are so familiar and the semantics by now so well elucidated that it seems a cheap comparison to make. If anything, the proliferation of cancer prototypes is so high that we might reasonably make the case that there is space for more variety and less convergence, due simply to the vast quantity of material.

²⁷¹ Though quite clearly not the full picture - who were the anorexics that must have existed in order for Bruch to write about them? - how can hearing about other anorexics on the radio *make* you one yourself? These are the sorts of questions that Hacking addresses in detail, so I will leave them for later in the chapter.

Another point which Showalter makes that should be considered is the role of fear in gestating hysteria. It is an underlying symbolic theme which runs through her work: where there is an outside force that creates unrest, there are people being made ill by it or understanding their disquiet in opposition to it. As Hacking states, ‘Showalter demonstrates how our recent hysterias have one thing in common, a tormented fear of some evil other, from outer space, or from the depths of the soul, or from federal agents, or from the vicious patriarch, or from poisonous gas cocktails in the desert’.²⁷²

But the conditions that concern us are at the other end of this scale from cancer and often conspiracy or outright paranoia for the most part represents a last resort and a fringe interest within the patient community. What we will see in the final chapter is that for many people, their first encounter with fibromyalgia or some other contested illness was not through a book or a TV show or some other media, but rather came through a reluctant doctor after months or years of diagnostic uncertainty. And even then, the information they were offered was hardly enough to construct an elaborate and consistent narrative identity. So the question here then is one of degree: in less well-known, less publicised cases, is there less of a prototypical tendency? Showalter would argue that the immense intertextuality of experience in contemporary society means that, whether we realise it or not, there are always narratives to act out or react against. She would also make the point that with conditions like chronic fatigue syndrome and fibromyalgia knowledge *is* widely disseminated, regardless of what patients’ claim. This is something I will return to in the final chapter.

Showalter makes one further point which I will quickly address. Writing in 1996, she makes explicit links between the surrounding political culture and the rate at which new conditions appear, expand in patient numbers and plays out. She claims that at the end of the 20th century a climate of political paranoia, anti-es-

²⁷² Hacking, I. 2002, p. 89.

tablishment feeling, millennialism and developments within the feminist movement (pejoratively labeled ‘victim feminism’) contributed decisively to the growth in numbers of people either being diagnosed or self-diagnosing themselves with new conditions. Though the western world has changed since then, we must ask about what ingredients we find in contemporary society that might likewise create an environment conducive to the sort of processes Showalter and Shorter describe. Where does medical authority stand now? To what extent does an individual privilege their own ability to generate knowledge about themselves over what others, professional and otherwise, tell them? What narratives are available, which are chosen and why? Are there patterns? The individual thinker who has done more than any other to bring these questions into focus and provide a theoretical framework for understanding them is Ian Hacking. The final section of this chapter will be devoted to him.

Hacking

A minor motif in Saul Bellow’s *Humboldt’s Gift* is the protagonist Charlie Citrine’s internal reflections on a beaver colony he visits whilst camping with his children. Next to the lake where the animals live, the Park Service put up a series of billboards which described and categorised the habits, activities and various natural cycles of the beavers. What strikes Citrine as profound is that ‘the beavers didn’t know a damn thing about this. They just went on chewing and swimming and being beavers’. This, he supposes, is the exact opposite of what happens when order is given to people: ‘we human beavers are all shook up by descriptions of ourselves. It affects us to hear what we hear. From Kinsey or Masters or Eriksen. We read about identity crisis, alienation, etcetera, and it all affects us’.

In other words, the study and theorising about a society alters those within it. When we are grouped or organised according to some principle or other, we react

to that grouping: we are happy or sad to see ourselves or be in seen in this or that way, we *change*. Citrine completes this observation by wishing that we could be more like the beavers, indifferent to whatever name or description is given to us.²⁷³

In a less prosaic way, Ian Hacking concerned himself with this ‘beaver problem’ for the best part of thirty years. What he set about trying to understand is the way in which classifying individuals acts upon those individuals, changes them as objects of knowledge and thus leads to a further change in classification as part of an ongoing process. This topic, detailed in a series of books and papers, has been termed his ‘Making Up People’ project. As he says, ‘it is about how a causal understanding, if known by those who are understood, can change their character, can change the kind of people they are that can lead to a change in the causal understanding itself’.²⁷⁴

This project has multiple aspects and asks more than the simple questions I have outlined above. Roughly speaking, Hacking does not just want to know how it is that categories affect those within them or future categories. He would also like to know how we can ourselves make use of this mechanism, and how it might influence the appearance or disappearance of what he has termed ‘Transient Mental Illnesses’ - those which seem to arise at a specific place and time and then for some reason fade away from public and medical consciousness. Furthermore, he wants to draw connections between questions of memory, questions of the self and questions of category; in other words, how is it that categorising objects of knowledge fundamentally alters the way individuals not only structure their experiences but

²⁷³ Citrine’s position in the novel is actually slightly more complicated than this, especially as it refers to residents of Chicago and German systems of classification. See Heidsieck, A. ‘Bellow, Styron, Roth: representation of anti-Semitism and its relationship to German cultural history in Jewish and non-Jewish American novels’ in Bogdal, K. M., Holz, K. and Lorenz, M. *Literarischer Antisemitismus nach Auschwitz*, 2007, Metzler, Germany, 2007.

²⁷⁴ Hacking, I. ‘The Looping Effects of Human Kinds’ in Sperber, D., Premack, D. and Premack, A. J. (eds.) *Causal cognition: a multi-disciplinary debate*, 1996, The Clarendon Press, UK, p. 351.

also the way they remember their lives and thus the very person that they believe themselves to be? - and, ultimately, can we use this information to change people's lives, to make them happier?

A multitude of kinds

One of the philosophical traditions in which Hacking situates his work is nominalism, or the naming of things. He argues that alongside natural kinds - that is, names for groupings that occur in the *real world* - we can place human kinds, which are categories that emerge from the social sciences. In his later work, Hacking dropped the 'human' and replaced it with 'interactive' and likewise refrained from talking of 'natural' kinds in favour of 'indifferent' ones, so I will use this terminology from here on in.

Without wanting to dredge through centuries of philosophy on the topic of natural kinds, it is enough to briefly describe the sort of object of knowledge that Hacking has in mind when he talks of 'indifferent' ones.²⁷⁵ What he means when he discusses such things are sets that exist (or indeed, simply *may* exist) in nature and which we have sought organised, scientific knowledge about. Some examples might be canonical, like the chemical elements, some fashionable (in the 90s when Hacking was writing), like quarks and some simply mundane, like a certain type of corn or particular species of tree. Hacking's realism is fairly broad, but this is not what is interesting. What matters to us here is not whether these objects exist or correspond to some actual reality, but that they are examined, grouped and studied yet remain unchanged by that process.

²⁷⁵ For a good discussion of natural kinds, see Dupré, J. *The Disorder of Things: Metaphysical Foundations of the Disunity of Science*, 1995, Harvard University Press, USA; for Hacking on natural kinds, see Hacking, I. 'A tradition of natural kinds' in *Philosophical Studies*, 1991, Vol. 61, No. 1, pp. 109-126.

Interactive kinds are, on the other hand, types of people that are conceptualised and ordered according to some agenda or other.²⁷⁶ Where indifferent kinds are the preserve of physics, chemistry, biology and all their innumerate subsidiaries, interactive kinds begin life in the ‘marginal, insecure, but immensely powerful’ social sciences.²⁷⁷ Hacking outlines them as follows:

‘By [interactive] kinds I mean kinds about which we would like to have systematic, general, and accurate knowledge; classifications that could be used to formulate general truths about people; generalisations sufficiently strong that they seem like laws about people, their actions, or their sentiments. We want laws precise enough to predict what individuals will do, or how they will respond to attempts to help them or to modify their behaviour’.²⁷⁸

Some examples of this would include women refugees, children with autism, people who commit suicide, alcoholics, multiple personality disorder sufferers and communists. Hacking sketches out four criteria in order to show what might qualify as a human kind. Firstly, he is thinking of kinds that are relevant to some people, that apply to some portion of the population. Secondly, these kinds must in the first instance organise individuals, their actions, their habits and behaviour. Thirdly, they should be kinds which are studied in the human and social science, groupings about which it has been deemed interesting or important to gain knowledge. Finally, Hacking adds clarity by saying that ‘kinds of people are paramount’.²⁷⁹ What he means by this is that only when the study of people transforms into our

²⁷⁶ ‘Agenda’ in this context does not, so to speak, have an agenda. I mean it merely to indicate that there must be *some* motivation present, nefarious or benevolent, in order to create a category of people.

²⁷⁷ Hacking, I. 1996, p. 352.

²⁷⁸ Ibid.

²⁷⁹ Ibid., p. 354.

idea of that sort of person does it become a human kind. If I research a certain set of individuals but that research does not produce any typological knowledge about their behaviour, their experiences, the casual links between their past and present surroundings and the way they ‘appear’ in the world, then I have not contributed to making a human kind.

As is immediately obvious, the variety of interactive kinds present in a particular society at any one time is immense.²⁸⁰ Some are too mundane to waste much thought over, such as perhaps (though maybe not historically) ‘left-handed people’, and, though qualifying as interactive kinds, the truths produced by our knowing about them will indeed be *so* general that there seems little point in pursuing them without qualification or some specificity. There does exist however, apart from these instances, an enormous number of what we might term *useful* interactive kinds. These are groupings on which we might want and hope to have an effect upon through understanding the nature of the effect of categorisation and the many tributaries which contribute to its general flow. They tend to be narrow enough to produce semi-solid truths about which we can talk with a degree of certainty not granted to those broader, more ambiguous groupings. It is these sets that Hacking is most interested in. They form the interactive kinds that he uses as examples and the groupings he thinks the most worthy of analysis.

The way in which he has separated these interactive kinds from indifferent kinds is contested. At its most fundamental, he distinguishes them by saying that the act of categorising an indifferent kind does not alter it, whereas placing an external theoretical structure upon an interactive kind does. As he states:

²⁸⁰ Though Hacking is at pains to note that his ideas apply only to his society - ‘My culture is my culture and none other’ - in Hacking, I. 1996, p. 351; and require an infrastructure of study - ‘All classifications that stick exist only within practices and institutions’ - in Hacking, I. ‘Between Michel Foucault and Erving Goffman: between discourse in the abstract and face-to-face interaction’ in *Economy and Society*, 2004, Vol. 33, No. 3, p. 285.

‘Inanimate things are, by definition, not aware of themselves... Take the extremes, women refugees and quarks. A woman refugee may learn that she is a type of person and act accordingly. Quarks do not learn they are a certain type of entity and act accordingly... The idea of quarks does not interact with quarks. Quarks are not aware that they are quarks and are not altered simply by being classified as quarks. There are plenty of questions about this distinction, but it is basic’.²⁸¹

I take this to mean that self-consciousness is one of the key distinctions between the two sorts of kinds that are being described. For my purposes this kind of rough-and-ready delineator is adequate, though critical responses have been forthcoming and will be outlined later in this chapter. I would however largely agree that ‘naming’ something has a different effect on that thing depending on whether or not it is able to absorb, reject or otherwise react to its ‘naming’.

A second way in which interactive kinds are said to be removed from indifferent ones is their dynamic nature. Not only does placing a person within a certain grouping, about which we suppose we have knowledge, change them, it also leads to an alteration of the grouping itself, because its subject entities have now shifted and become something else. This means that when we create an interactive kind what we have produced is a moving target. Dynamic nominalism, as this is known, is ‘the belief that systems for classifying people created by society may affect what people do, which may in turn affect our knowledge of them’.²⁸²

If Hacking is hyper-aware of anything, it is that none of his rules will apply in all circumstances. This is especially evident when he says that no interactive kind will operate in precisely the same way, but even of the above distinctions he is reluctant

²⁸¹ Hacking, I. *The Social Construction of What?*, 1999, Harvard University Press, USA, p. 32.

²⁸² Schmaus, W. ‘Sociology and Hacking’s Trousers’ in *PSA: Proceedings of the Biennial Meeting of the Philosophy of Science Association*, 1992, No. 1, p. 169.

to be dogmatic. He splits up types of interactive kinds and produces sub-theories for each, some of which contradict his more general thoughts on how to tell one kind (interactive or indifferent) from another.

For example, he recognises that in some cases the individual does not *themselves* need to be aware of a classification which applies to them. It is enough in these instances for the surrounding social environment of the person to be influenced. An example he uses to illustrate this – a type of interactive kind he terms inaccessible – is autistic children. These types of people are ‘human beings who cannot understand’ and for whom there ‘cannot be self-conscious feedback’.²⁸³ However, what does possess self-consciousness is the ‘larger human unit’ that the autistic child is situated in, and this can change depending on what knowledge is produced about the individual in the centre. Thus, as causal understandings change over time (from feeble-mindedness to childhood schizophrenia to refrigerator mothers to theories of mind etc.), the immediate social and institutional environment of the person so-described is altered. Individuals may also fall in and out of classification depending on such alterations.

This type of kind is important because it appears to challenge Hacking’s foundational distinction of self-consciousness, but he does not take it to be a critical flaw. Rather, by expanding the unit of classification beyond the individual to their immediate social surroundings, he thinks he is purporting a broader self-consciousness and making the same point – organising a set of qualities and attributing them to a group of people changes both the people and the group – about autistic children as about any other interactive kind.

Inaccessible kinds are not the only subdivisions of interactive kinds that Hacking outlines. He also includes administrative, second-order, biologised and self-ascrip-

²⁸³ Hacking, I. 1996, p. 374.

tive kinds in his analysis.²⁸⁴ It is the last two of these which I think are of most relevance here, and which I would like to discuss.

‘Biologised’ kinds represent for Hacking one of the most important and powerful trends in scientific and social thought at the end of the 20th century: the move towards finding genetic or neurological explanations for behaviour that was previously explained as social or environmental.²⁸⁵ What we find with biologised kinds is that they have a tendency to possess an amorality or absolve responsibility for certain actions. A kind of people whose causal matrixes are formed at birth are different from a kind who *decide* to do something, based on some other reason and influenced by other factors.

This can lead to an interesting tension between competing frameworks which both claim to explain the same phenomena. Hacking gives the example of alcoholism, where one framework – Alcoholics Anonymous – produces knowledge about alcoholics which is explicitly moralistic and thus creates a different kind of person than that produced by a biologised explanation which ‘blames’ genetic inclination towards addiction. Which kind becomes dominant depends on the social context in which the kind is expressed; which kind fits in most with people’s preconceived, existing ideas of that sort of behaviour? – who speaks from the position of most authority when defining the kind? – which kind aligns most with other trends present? –

²⁸⁴ Briefly, the first two kinds not discussed at length are as follows (bear in mind there is significant overlap between them and the others). Administrative: kinds created by the categorisation of people into administrative entities, i.e. the interaction between census criteria and those who fall within census criteria (‘Hispanic’ is given as a good example). Second-order: these are kinds derived from a primary concept, the most prominent being normality. Once you have an established ‘norm’ in relation to whatever it may be, deviations from this produce ‘abnormal’ kinds, the interactive axis being between individuals’ perceptions of themselves and their perception of what it is to be ‘normal’, alongside an evaluative element that judges how much this matters, whether it is positive etc.

²⁸⁵ Hacking does point out that this is in some sense a rerun of previous research programmes from before WWII and in the 19th century, but what is different here is both the sophistication of the tools and the lack of an specific ideological driver beyond reductionism and moral exculpation for all within the kind (rather than, say, a specific race).

which kind of kind do people most want to be? In many cases there is no ‘winner’ so to speak, and different kinds have precedence in different situations.

When he talks about ‘self-ascriptive’ kinds, what he is referring to is an inversion of the traditional way in which interactive kinds operate and have operated. Roughly speaking, pre-1950 (according to Hacking), the two axes of the social science – a positivist aping of natural science methods and interpretations of causation and the bureaucratic-statistical mass collection of data – combined to loosely create between them the knowledge and the known. Speaking from the point of view of experts, be it census collectors, sociologists, psychiatrists or whomever, “we’ know about ‘them’”.²⁸⁶ That is to say, there is a one-directional model of knowledge production. The known-about remain passive and do not contribute to the creation of knowledge about themselves, except in a subconscious manner. What we have seen since then, says Hacking, is the explosion of a different sort of process, whereby the ‘known may overpower the knowers’.²⁸⁷ This inversion is even more marked now than when Hacking was writing, with identity narratives prevalent across the western world which prioritise and valorise self-identification.

This is where the objects of knowledge themselves lay claim to the epistemic process, and begin opting in or out of a category, generating and disseminating new information and generally challenging the moral scaffolding of the grouping. What is different about these ‘self-ascriptive’ kinds is that the motivation behind ‘reclaiming’ or ‘reframing’ the interactive kind is almost universally attempted in order to benefit those under description. Classifications can affect the way we evaluate our personal worth, and frequently they represent straightforwardly moral distinctions. Because of this, it can be greatly in the interest of an individual to try and deliberately shift the grouping they believe they are a part of towards something that allows them and others like them more self-respect and emotional con-

²⁸⁶ Ibid., p. 381.

²⁸⁷ Ibid., p. 359.

tentment, as well as better treatment by others and by institutions whose actions in relation to them are directly organised on the basis of their category.

The canonical example in this respect is homosexuality, which during the last hundred years or so has gone in the west from a top-down, (pejorative) medical description of behaviour to a contested psychiatric diagnosis to a ‘lifestyle choice’ to a relatively accepted, in some places, way of biologically *being*, with many stops and reversals in between. What is key to this process is the way in which the ‘known’, homosexuals, fought with the ‘knowers’ over the category that came to a greater or less extent to define them, and to some degree gained control of the agenda.

These two types of interactive kind often intersect. This is because, notwithstanding famous exceptions such as Alcoholics Anonymous, self-ascribing kinds push towards biologising as a way of creating a more positive, less stigmatised kind to belong to. This process occurs in virtually any kind in which those involved both feel they are held responsible for their (negative) actions by some portion of society and that their moral condition could be alleviated by pursuing a biological explanation.

To bring this discussion full circle, it is the presence of a moral dimension which is the final substantive wedge between indifferent and interactive kinds. Interactive kinds are imbued with intrinsic normative qualities in a way that indifferent kinds are not. To put it starkly: ‘caked mud and polarized electrons may be good or bad depending on what you want to do with them, but child abuse is bad and multiple personality is a disorder to be healed’.²⁸⁸

Hacking is aware that this approach does not accurately outline all of the various links between institutions and the types of people they describe, or indeed the form that those many variations might take. What I believe he is articulating is a belief in the plurality of interactive kinds but also a conviction that this plurality is trivial.

²⁸⁸ Ibid., p. 366.

Every interactive kind will be different in some way, both from those around it and those that came before, but like Wittgenstein's famous family resemblances, each will have similarities with some others and the overlapping mesh will grant us enough similarity to speak with relevance about them as a group. It is not just regarding interactive kinds that Hacking is a pluralist, but also about the *looping effect of interactive kinds*, a conceptual innovation which we will now examine.

The looping effect of interactive kinds

As outlined above, the most fundamental differences between indifferent and interactive kinds are the self-consciousness, moral content and dynamism of the latter.²⁸⁹ The mechanism by which these special features affect the categorisation itself and generate a 'moving target' has been termed 'the looping effect' and is key to understanding how producing new knowledge about people causes them to become different and thus our understanding of them to change in an ongoing process.

Essentially, when a category of people is delineated from society on the whole, and knowledge is created and disseminated, institutionally, instrumentally or in some other manner, the individuals in question react. This reaction appears under many guises and is never exactly the same across different kinds. However, in all cases it creates a type of person who is different from that originally under study, with new causal truths and new typologies. Thus the original category is now no longer isomorphic with the object of study, and so must itself change to catch up, assimilating or rejecting the new knowledge in the same way that the individuals did in the first place. This unfolding and permanently unfinished relationship is what Hack-

²⁸⁹ It is worth noting that at one point Hacking does argue that something can be *both* an indifferent kind and an interactive one, which seemingly contradicts most of what he writes elsewhere. See Hacking, I. 1999, pp. 108-124.

ing calls the 'looping effect'.

His best and most extensive example of this is multiple personality disorder, now called dissociative identity disorder, which he chronicled in *Rewriting the Soul*. In this work he outlined two main processes. Firstly, he showed how memory came to be medicalised as a surrogate, secular soul and how trends in the study of hypnotism, fugue, sleepwalking, hysteria and epilepsy shaped this. Secondly, he demonstrated how similar issues of memory and the self played out in a completely different arena: multiple personality disorder (MPD) in 1980s America.

His account, simplified, goes like this.²⁹⁰ From the first (modern) diagnosis, a prototype 'multiple' is produced and some knowledge about them is distributed. Then, as more psychiatrists become aware of the diagnostic category, more patients begin to appear and attract press attention. Furthermore, the category itself begins to move, or 'wander'. Where once it was a condition that typically presented in patients as a splitting of personality into one or two 'alters' (that is, alternate personalities), soon patients were appearing with more and more, hundreds even. Being abused as a child is identified as a key causal link to adulthood MPD and this becomes a well-known 'fact' about the condition. Patients who do not recall being abused are encouraged to search their memory and in some cases false memories are recalled, with all the family-splitting acrimony that inevitably arises from incorrect accusations. Journals are started about the condition, conferences are organised and all the while patient numbers grow and grow. There is a backlash: the False Memory Syndrome Foundation is formed to combat misremembered or entirely untrue allegations of sexual abuse made by patients against family members whilst some psychiatrists begin to embark on treatment programmes contrary to orthodoxy.

What we witness here, says Hacking, is the complicated interplay between individuals, institutions and the knowledge that flows from one pole to the other. Narra-

²⁹⁰ Hacking, I. 2002.

tive similarity in patients becomes regarded as evidence for this or that law-like regularity, which in turn suggests to patients that this is a way of structuring their experience. Morality flickers in the background at all stages, steering decisions made by professionals and those caught up in it all, the families and friends of patients. Those themselves who sit at the centre of the whole thing, the individuals in the group, being told what it is they have by different sources, begin to see themselves as someone new, someone different from before. In doing so, says Hacking, they also *become* something different from before, an original type of person:

‘We think of many kinds of people as objects of scientific enquiry [and] we think of these kinds of people as given, as definite classes defined by definite properties. As we get to know more about these properties, we will be able to control, to help, to change, or to emulate them better. But it is not quite like that. They are moving targets because our investigations interact with the targets themselves and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. That is the looping effect. Sometimes our sciences create kinds of people that in a certain sense did not exist before. That is making up people’.²⁹¹

It is this last point which is the most profound that Hacking makes, and which is vital to understanding the whole enterprise. When he speaks of ‘making up people’, what he is referring to is not just a process whereby people evolve. He is articulating something different: categorising people creates not just a modified version of that group but whole new people, people that didn’t and couldn’t have existed before.²⁹² The restructuring of experience which comes with new cate-

²⁹¹ Hacking, I. ‘Kinds of People: Moving Targets’, *The Tenth British Academy Lecture*, 2006.

²⁹² I mean this in a metaphysical sense: the components of selfhood necessary to view yourself in a certain manner, to understand and, more viscerally, *process* new experiences, did not exist previously, and therefore *being* this sort of person was not an option.

gories and creates new, distinct selfhoods is the final piece of the puzzle required to understand Hacking's interactive kinds.

It is banal to state that as we gain knowledge about the world we begin to organise our experience of it differently. Understandings of the external world and who we are as people lead us to interpret situations and phenomena in ever unfolding ways. To use some archetypes, a writer may find that they can no longer enjoy the simple pleasures of watching a sunset without the internal compulsion to translate it into prose, the art lover may become unable to hear of an event without picturing the scene in the manner of a corresponding masterpiece and the economist might find themselves frequently conceptualising events according to pieces of financial theory. These restructurings of experience are constant and multifarious: the first time I drove on the motorway at night, for example, I was viscerally reminded of racing games I used to play as a child on the PlayStation, that previous embedded experience informing how my mind processed sensory information in the present.²⁹³

How Hacking makes use of this idea is far more significant however. He says that new categories of people, new interactive kinds, give individuals unanticipated and unpredictable tools with which to understand their pasts. So it is that with the rise of 'child abuse' as an interactive kind, people began more and more to view themselves as abused and to slot into *that* kind. They restructured their past experiences in light of current knowledge, and so what was viewed as one thing became another. This is important because for Hacking memory is key in modern western societies to understanding the construction of self.²⁹⁴ Memory makes us who we are,

²⁹³ A character in the Jean Thompson short story *Applause, Applause* puts it like this: '...this heightened self-awareness was a sign of strain. As if he couldn't really escape his work or the persona that went with it. The Artist's impressions of a walk in the woods. The Artist's view on viewing. The Artist on Art...One ended, of course, by losing all spontaneity. You saw people as characters, sunsets as an excuse for smilies...'

²⁹⁴ I mean construction in the strict sense here, i.e. of composite parts, rather than 'social' construction.

and if our memory changes, then we become a new type of person.

This process is described as follows:

‘New meanings change the past. It is reinterpreted, yes, but more than that, it is reorganised, repopulated. It becomes filled with new actions, new intentions, new events that caused us to be as we are. I have to discuss not only making up people but making up ourselves by reworking our memories’.²⁹⁵

More specifically, regarding MPD, Hacking states that:

‘A certain picture of origins is imported to disturbed and unhappy people, who then use it to reorder or reorganise their conception of their past. It becomes their past. I am not saying their past is directly created by doctors. I am saying that this picture becomes disseminated as a way of thinking of what it was like to be a child and to grow up. There is no canonical way to think of our own past. In the endless quest for order and structure, we grasp at whatever picture is floating by and put our past into its frame’.²⁹⁶

Though I would take issue with the ambiguity of his final sentence, on the basis that some ‘pictures’ are more convenient for our mental and moral well-being than others and therefore more likely to be chosen, I think he makes an important point about categories, memory and self-conception. Only when we appreciate that knowledge production about a set of people can deeply, fundamentally alter the way they are can we see the true power of the looping effect.

This restructuring does not of course only extend backwards. New categories also

²⁹⁵ Hacking, I. 2002, p. 6.

²⁹⁶ Hacking, I. 2002, p. 88.

create new possibilities for understanding experience extending into the future, and more dramatically, for new actions. To use a current example, the proliferation of a certain type of pornography (misogynist, violent, demeaning to women) since the 1990s and especially following its widespread and inexpensive distribution on the internet has probably had an effect on the way that many individuals conceptualise 'normal' sexual relations, even if that effect is not mimicry but more a subtle shift in expectation. Further to this internal reclassification, it has produced prototypical sexual experiences and normalised what were most likely to be in the past relatively rare sexual events. In many cases, it is simply that individuals had fewer modes of action from which to choose from previously, and the expansion of the possibilities given to them leads to a pattern of behaviour which is self-reinforcing. Hacking makes this point regarding the dissemination of information about child abuse: not only did it lead people to come to see themselves as abused, it also *gave abusers ideas*. One thing that I think is worth mentioning is Hacking's desire, with MPD, to describe and analyse an interactive kind that was still in motion. A reason why he did this was to show how types of people that may seem concrete categories are actually in an undulating and messy state of constant redescription, and that this is happening all around, all the time. Though possible contemporary instances of this abound, I think the transgender movement is an almost-too-perfect case of this 'still in motion' kind.

Over the last decade or so, we have witnessed a significant growth in the number of people who identify themselves as being transgender. This has come to be seen as a far wider grouping than its antecedent category, transsexual, with a diverse array of meanings, terminology, medical and commercial infrastructure. Though the past can be bent into all kinds of shape by well-meaning activists looking for historical validation, I am confident that what we are seeing here is, in Hacking's sense, a *new* type of person rather than learning more about a constant human state. As Carl Elliott writes (of transsexuals), 'fifty years ago the suggestion that tens of thou-

sands of people would someday want their genitals surgically altered so that they could change their sex would have been ludicrous. But it has happened'.²⁹⁷

In transgender people we have all the outward features of an interactive kind – the conferences, the journals, the patient organisations, the jargon, the expansion of people identifying themselves as being that way etc. But we also see this intriguing forwards/backwards realignment of meanings; individuals who come to have possession of knowledge about themselves begin reinterpreting the past and the future, and do so in a way which is novel, which has not happened before. The transgender person of today, fighting back against an irreducible cocktail of biologically and culturally defined gender roles, living their life in a societal and political context in which self-ascribed personal identity has reemerged as a pivotal force, seeing themselves as a manifestation of, alongside many other things, the right to choose your own way of seeing gender, is a different kind of person to the boy in the 1980s who liked wearing women's clothes because they made him feel more at peace, was regarded as effeminate and grew up to be a gay man. They are probably even substantially different from the transsexuals seeking surgery that Elliott was referring to in 2000. These things move fast.

Placed together, Hacking's ideas about interactive kinds, the looping effect and the reconstruction of self are an attractive and poetic explanatory framework. Before I deal with his critics, I will briefly describe one more set of conceptual apparatus that he has bestowed upon us.

Ecological niches

Like Shorter and Showalter, Hacking is interested as to why it is that some conditions 'appear' at certain times in certain places and then seem to fade from view. He terms this sort of disease a 'transient mental illness' and wonders what it is

²⁹⁷ Elliott, C. 'A New Way to Be Mad' in *The Atlantic*, December 2000.

about the cultural backdrop at the time which causes it to spread or die out. He is not here overly concerned with the symptoms of the patients or uncovering what they ‘really have’. Rather, he tries to build a framework, loosely similar to ideas discussed earlier in this chapter, through which it is possible to understand why some diseases are so, or appear so, specifically bound to a culture or set of similar cultures, at one time.

The metaphor he employs to illustrate this framework is that of an *ecological niche*, a term borrowed from ecology that ‘invites us to think of life in all its rich bio-complexity’.²⁹⁸ He uses it as a way of demonstrating his commitment to the complicated nature of these diseases, conditions for which simple modelling will never provide a complete picture. When he says ‘ecological niche’, he is referring to various aspects of medical, social and institutional life which enable or restrict the manifestation and proliferation of a disease. These different features of the societal landscape he terms vectors, each with the capacity to provide part of a home for a condition at any one time.

To use his example, fugue states in France and Europe generally (though not Britain or the United States) around the end of the 19th century, found a place in each of the four vectors he provides: medical taxonomy, cultural polarity, observability and release.²⁹⁹ Fugue could be allocated a space in medical understanding, either as hysteria, epilepsy, or both. This meant that it did not represent a challenge to existing knowledge structures, but that it also posed a problem of precise classification to be solved. Culturally, fugue was positioned between the moral antipodes of tourism and vagrancy, both of which were of great general interest at the time. It was also observable: due to conscription laws and fears of absconding there existed in Europe a surveillance system designed to stop young men travelling from place to place without reason. Finally, it served as a release for lower middle-class

²⁹⁸ Hacking, I. 2002, p. 81.

²⁹⁹ Hacking hints that more vectors might be available but does not provide them.

men in stable but poorly paid employment. Not poverty-stricken enough to be vagrants, not rich enough to be tourists, they moved around in a netherworld.

The use of this framework helps Hacking to answer one of the questions he sets himself, namely ‘why France? Why not Britain or the United States?’ The answer being that two of his four vectors are not present in those societies. Vagrancy was not a social problem of any great importance and individuals were free to travel without papers or pressure to account for their appearance in any particular location. In societies lacking all or some of these vectors, a wandering man might be many things, but they were not, and did not come to see themselves, as suffering from a mental illness. As Hacking, talking about a place that Albert, his central fuguer, once wandered, puts it:

‘There on a flowery slope or on a wind-blown outcrop you may still encounter a nervous man who was hoping not to be seen. Today he is more likely to be a confused Moroccan making his way gingerly through to France than a dazed French infantryman heading for the safety of Spain. Today he is just a mixed-up illegal immigrant. Ninety years ago he suffered from a distinct mental malady, ambulatory automatism’.³⁰⁰

How this metaphor might help us to understand current conditions is fairly clear. Like other work discussed above, it asserts the necessity of a cultural environment which is conducive to certain types of behaviour and certain ways of understanding that behaviour. The soil must be fertile, in other words, for some conditions to grow. What Hacking is not doing is downplaying other causal mechanisms, whether they are environmental, neurobiological, the result of childhood trauma or some other agent. He is just asserting the multiplicity of circumstances that must align in order for a disease like ambulatory automatism (fugue) or MPD to

³⁰⁰ Hacking, I. 2002, p.79.

appear and ‘thrive’.

I think this schema has wide applicable potential. If we use it to analyse fibromyalgia for example, we come up with a plausible explanatory framework, based on Hacking’s vectors.³⁰¹ We see that by placing this disease within Hacking’s schema, we might begin to understand how it would appear to come about at a certain time in history but not others. The following is speculative but potentially useful:

Medical taxonomy: fibromyalgia does fit into a medical taxonomy, or rather, several. It has a ICD code and is recognised by many as coming under rheumatology’s domain. Articles are written about it in various journals and though its classification is problematic, it is problematic in a way that accords with expectations, and alternate explanations (mostly related to somatisation) simply slot it within some other taxonomy. In other words, it can be understood in a variety of recognised ways, the important feature here being that it *can* be understood.

Cultural polarity: Hacking states that conditions like fibromyalgia exist between two cultural poles, one of vice and one of virtue. This can be a slightly tricky vector to pin down, but in the case of fibromyalgia it might be argued that patients are caught between narratives of health, wellbeing and employment and the persistent rhetoric attacking those who claim welfare as ‘scroungers’, ‘malingerers’ etc. Individuals with fibromyalgia cannot fulfil their role as able-bodied, participatory economic agents but equally recoil from being associated with the lazy, the feckless, the ‘undeserving’ or ‘conniving’ poor. In the gap between these two points they find themselves, both unable to work and unwilling to associate with what has been culturally presented as the alternative.

Observability: since the American College of Rheumatology released its diagnostic criteria in 1990, the ‘18 tender point’ test has been used in order to identify fibromyalgia patients. Recently, following studies which showed this test to be incon-

³⁰¹ See Chapter IV for more details on fibromyalgia.

sistent, a broader diagnostic approach was adopted. The tender point test now forms one part of the criteria, performing a less central role. The nature of the condition means that developing more incisive, reliable instruments is difficult, but the presence of such a tool, however problematic, does mean the fibromyalgia is more likely to be offered as a diagnosis. You can still see something through cloudy glasses.

Release: for patients, fibromyalgia might provide a release in several ways. It could be a bodily expression for some unknown, suppressed pain. Or a way for the body to secure near-permanent relief from an overly stressful lifestyle. Both have been postulated and might be considered. Personally, I find the overly symbolic nature of this vector troubling. It seems to me a recipe for selection bias and may be of little use in explaining conditions like fibromyalgia.³⁰²

What we can see from this exposition is that there *are* certain aspects of the modern medical and societal landscape that seem as though they might contribute to fibromyalgia and other similar conditions' 'possibility'. That is to say, following Hacking's vectors would allow you to formulate fairly extensive answers to the questions: why fibromyalgia? - why now and not in 1950?

Criticism and discussion

I have now outlined Hacking's main ideas in relation to the topic at hand. I think his work on this area provides us with a feast of food for thought, and criticisms of his project tend to respect his innovation and invention if not all of the details of his speculation. The critical angles of attack have tended to come in two forms: either taking issue with his ontology regarding the clear cut, fundamental distinction between interactive and indifferent kinds or questioning the specifics of his

³⁰² I am of the firm belief that a great majority of people are conceivably in need of 'release'. We only notice when we start looking for it.

mechanisms. There is a third line of criticism, which is that his demarcation of interactive and indifferent kinds does not form a cogent method of separating the natural sciences from the social.³⁰³ I will not pursue this line of enquiry as these questions do not concern us here.

The first of these critical approaches, favoured in different ways by Khalidi, Tsou and Cooper, focuses on perceived inconsistencies in the way in which Hacking delineates interactive from indifferent kinds.³⁰⁴ Essentially, say the critics, there is not quite such a firm line to be drawn between the two. Khalidi demonstrates convincingly that classifying certain objects, such as making marijuana illegal or conceptualising livestock as food does change the objects themselves and creates a moving target, in the same way it does for people.³⁰⁵ If the defining feature of an interactive kind is that it is influenced by our classifications and then loops back and changes the classification, he surmises that this phenomenon ‘is not confined to the human or social realm’.³⁰⁶ Where Khalidi takes this argument is towards a discussion of the realism about kinds. Whether or not kinds are mind-dependent, or in what way they are mind-dependent, seems to matter little to my concern here, namely how they might affect individuals with contested diseases, so I will leave this criticism as is.

Tsou highlights what would appear an outright contradiction in Hacking’s writing: he (Hacking) states that looping is the distinguishing feature between indifferent and interactive kinds, which are mutually exclusive *on that basis*, yet also makes the

³⁰³ For an example of this sort of critique, see Drabek, M. L. ‘Interactive classification and Practice in the Social Sciences: Expanding Ian Hacking’s Treatment of Interactive Kinds’ in *Poroi: Issues in the Rhetoric of Science and Technology*, 2009, Vol. 6, No. 2, pp. 62-80.

³⁰⁴ For similar criticism, also see Bogen, J. ‘Comments on “The Sociology of Knowledge about ‘Child Abuse’”’ in *Nous*, 1988, Vol. 22, pp. 65-66.

³⁰⁵ Khalidi, M. A. ‘Interactive Kinds’ in *The British Journal for the Philosophy of Science*, 2010, Vol. 61, No. 2, pp. 335-360.

³⁰⁶ *Ibid.*, p. 358.

claim that there are some human kinds which are both indifferent and interactive.³⁰⁷ What Hacking is trying to account for is psychopathology, where it is likely that in future some definitive underlying neurological process will be identified for say, childhood autism. Then we will find ourselves in a position where the category – ‘childhood autism’ – refers to an indifferent kind (in his example it is hypothesised as pathology *P*) and an interactive one (the children themselves, who are shaped by their category and in turn feed back into their classification). He partially explains how this would be possible with an appeal to Putnam’s semantic distinction between referents and stereotypes, with the pathology (and therefore indifferent kind) being the referent of a given classification and the stereotype being the set of meanings, actions under description, attitudes associated with the classification (the interactive portion).

Tsou argues that Hacking is being inconsistent, and that he has conflated a lack of looping effects with the potential existence of identifiable biological regularities. He concludes that this is just one of several instances in which Hacking equivocates on the separation of interactive and indifferent kinds in relation to their definition. We should not therefore base our understanding of what constitutes each type on their distinctions.

Cooper also focuses on the way in which the two kinds are delineated. She questions the legitimacy of cultural feedback loops as distinguishing features in a similar vein to Khalidi and says that conceptually Hacking has misunderstood

³⁰⁷ Tsou, J. Y. ‘Hacking on the Looping Effects of Psychiatric Classifications: What is an Interactive and Indifferent Kind?’ in *International Studies in the Philosophy of Science*, 2007, Vol. 23, No. 3, p. 334; This confusion is not helped by the fact that Hacking switches from talking about human kinds to referring to them as interactive, only to then seemingly adopt the former label as a sort of umbrella term. It is perhaps inevitable that conceptual confusion begins to creep in when you write three books and a dozen articles about the same topic over a couple of decades.

Anscombe's intentional actions under description argument.³⁰⁸ What she aims to show is that because description is not *needed* for novel action, or indeed for any intentional action at all, there is no strong logical link between new descriptions and new actions or types of people. She believes that this causes the conceptual level of his argument (related to the necessary self-consciousness of human kinds) to deflate back into being solely one of cultural feedback, which she has shown to be problematic.³⁰⁹ This leads her to conclude that he is wrong to say that interactive kinds cannot be indifferent kinds.

Her argument is flawed though, in two senses. Firstly, when discussing the possibility of action without description, she uses the example of a cave man called 'Ug' who, she claims, would be unable to do anything in Hacking's world because nothing had been described yet, alongside the example of a bird landing on a branch with both bird lime and seeds on it, an action we can interpret by considering the bird's nature and without requiring the bird to be aware of a description:

'...as there are other means of inferring an actor's intentions which do not depend on descriptions, it cannot be concluded that descriptions are essential for intentional actions. Ug can intend to make a fire, and the bird can intend to land on the twig, without any descriptions being required. In such cases Hacking is simply wrong to claim that descriptions are required for intentional action'.³¹⁰

³⁰⁸ Cooper's paper was written first, so technically it is the other way round: Cooper, R. 'Why Hacking is wrong about human kinds' in *The British Journal for the Philosophy of Science*, 2004, Vol. 55, pp. 73-85.

³⁰⁹ Cooper argues that cultural feedback poses problems for Hacking because plenty of 'indifferent' kinds appear to be changed over time by societal classifications - for example prize cattle or the marijuana plant, both significantly altered as a result of their assignment to this or that group.

³¹⁰ Cooper, R. 2004, p. 82.

This counterargument fails, however, because Hacking is explicit about the modernity of his theory; it requires the existence of vast social science infrastructure, mass communication and many other factors besides in order to be applied. It is very far away from cave men.

Secondly, her idea of Hacking's conceptual vision is extremely oversimplified. He is not arguing that people did not or could not act in certain ways before a category was created that allowed them to do so, he is saying that the production of category causes new meanings to congeal around action (and a lot more besides). So in a sense an action becomes 'new' not because it could not have been performed before but because if it was it would have been performed under a different psychological understanding. I could have had sex with another man five hundred years ago, but I could not have done so as a 'gay man' in the modern sense. Cooper seems to have missed this distinction.

She does, however, conclude by stating that she is 'happy for Hacking to be right about a great many things' and seems to accept that her work has not harmed the conceptual core of his project.³¹¹ Tsou says something similar, that he does not think that the 'conceptual flaws' he identified in 'Hacking's presentation are necessarily fatal to his overall theory'.³¹²

I think these final comments are key. Even if the strict dichotomy between the two types of kinds needs to collapsed, redefined or extended this does not alter the most important points Hacking makes. The looping effect, ecological niches, the restructuring of experience/memory/selfhood...all remain valid conceptual innovations regardless of whether sometimes interactive and indifferent kinds appear to overlap. For my purposes, slight conceptual confusion, blurred ontology and minor inconsistency are acceptable so long as they do not interfere with the lessons Hacking might teach us about the experience of contested disease patients. And, on the

³¹¹ Ibid., p. 80.

³¹² Tsou, J. Y. 2007, p. 335.

whole, I do not think that they do.

The second critical approach to Hacking, which focuses on mechanisms, poses more of a problem. Put simply, his ideas are too messy for some critics. There is no concerted attempt to accurately model the looping effect, and at times his descriptions impart a sense of what he means, but not a definitive capsule of thought. As Kuorikoski and Pöyhönen say, he only points ‘towards an interesting phenomenon without providing the resources for systematic modelling, analysis, and ultimately, explanation’.³¹³ Indeed, this is one of the reasons why I quote him at such length above. Hacking in small segments does not make sense.

Tekin makes a similar point to Kuorikoski, stating that, in particular, ‘the causal trajectory in which looping effects are generated and the way in which the subject responds to being classified remain unclear’.³¹⁴ It seems that one strength of Hacking – his appreciation of complexity and multiplicity, his simple, open-minded pluralism about how the looping effect will apply – is also a weakness. That we are able to get a strong idea of what he means is no consolation if we are not able to map it in a constrained conceptual manner. There is a danger that this reduces its usefulness as a tool, which is a far more serious and potentially damning criticism than the first critical thrust outlined above.

Hacking has stated that he has been accused of being too ironic in his intellectual stance and that people complain he places too much space between himself and

³¹³ Kuorikoski, J. and Pöyhönen, S. ‘Looping Kinds and Social Mechanisms’ in *Sociological Theory*, 2012, Vol. 30, No. 3, p. 188.

³¹⁴ Tekin, S. ‘The Missing Self in Hacking’s Looping Effects’ in Kincaid, H. and Sullivan, J. A. (eds.) *Classifying Psychopathology: Mental Kinds and Natural Kinds*, 2014, The MIT Press, USA, p. 227.

his subject matter.³¹⁵ The basic claim is that his style negates taking a stand. I disagree with this assessment. His writing does obscure his position, it is true. Partly this is down to his distaste from social constructivism, to him an overtly moral exercise and one which he wants to distance himself from.³¹⁶ Partly too it is because he writes about topics which are current and which inspire histrionics, another style of expression he wants to avoid.

However, beneath this, there *is* a quiet but distinct moral agenda. He is not interested in telling people how to live their lives, or in saying that there is a right way to remember your life or to structure your experiences. He is not arguing in favour of one kind of identity over another. But what he is saying is that people are unhappy and that they may be being harmed by some of the processes he has outlined. Previously stable or treatable people may come to understand themselves in a way which is not amiable to their recovery. The meanings that guide their lives may have been hijacked by one force or another. By mapping these mechanisms, by understanding the different ways in which these things can occur, I think Hacking is hopeful that in some small way we might be able to gain a measure of purchase on their levers. Especially in light of his work regarding memory, identity and the soul, it is fair to say that in some instances the stakes are very high indeed.

This is why it is particularly worrying to consider that his causal understandings may be more incomprehensible than the ‘complex and shady’ description of them

³¹⁵ ‘There’s too much irony in my work, there really is...People often ask: so you’ve given us all the options and you’ve given us good things and bad things about all of them but what the heck do you think?...In general it is a defect in the way that I proceed that I am often very ironical’. In Hacking, I. Holberg Prize Lecture, *The Holberg Prize Symposium*, 2009.

³¹⁶ Though reading *The Social Construction of What?*, you get the distinct feeling that a large part of his problem with social construction is linguistic: he has a certain definition of ‘construction’ in mind, that of various materials being gathered together and employed to create something new, where a plan is followed according to an agenda etc., which makes the metaphor as it is used in the humanities look decidedly lazy.

he allows.³¹⁷ Without some degree of applicability, this theory is unable to gain any traction on individual units of study, or be usefully engaged on subjects outside of his own examples.

This is a problem not just of conceptual messiness, but also of specificity. By adhering to a model of looping which assumes each and every instance of looping will be different in some way, there is a risk that we arrive at a situation where every phenomenon requires in-depth, rigorous and extensive historical research in order to be understood. By the time we are able to do this, to work out the particular manifestation of interaction in any given case, that case is likely to have moved on, the 'target' advancing in new and unpredictable directions.

The question, then, is twofold. Hacking is 'explicitly sceptical about the possibility of generating a substantial and generalizable theory of the looping effect' and 'he appears to think that forms of looping are too varied and always highly dependent on specific sociocultural contexts'.³¹⁸ So does this mean, firstly, that his theory is in fact fairly blunt?- and could it be modified, clarified or extended in a way that sharpens it?

Kuorikoski and Pöyhönen do not answer these questions but suggest a direction of travel towards answers. Their aim is to move the discussion and analysis of looping effects away from a philosophical debate about the ontological status of social reality and towards empirical discussion, theorising and data collection. I second this intention: looping effects may well act as neat devices in the ongoing natural kind discussion, but they are first and foremost an empirical phenomenon which appear to casually dictate certain social relationships, for better or worse. Pinning this down is, to me, a more useful exercise.

Their suggestion is to privilege mechanistic explanations, which steer clear of con-

³¹⁷ Hacking, I. 1996, p. 351.

³¹⁸ Kuorikoski, J. and Pöyhönen, S. 2012, p. 194.

structionism and essentialism. They believe that mechanistic accounts align most accurately with the practices of classification in both the natural and the social sciences, and they believe that further study should aim at providing middle-range, casual theories of social phenomenon. Work like mine, which pays close attention to the patient experience whilst retaining theoretical frameworks such as Hacking's is in this tradition.

One final critique, to my mind the most sophisticated, has been provided by Tekin. Like others, she identifies the complexity and ambiguity in the casual trajectory of the looping effect as a shortcoming of Hacking's approach. She separates this issue into two problematic elements: the lack of an empirically and philosophically cogent account of the self, which sits at the centre of Hacking's theory but is never satisfactorily articulated, and the failure to properly engage with the manifold complexity of psychopathology.

In addressing the first of these sub-problems, the 'missing self', Tekin argues that by showing the looping effect through large examples, Hacking has negated providing us with a cogent explanation of exactly *how* and *why* the looping effect influences subjects, causing them to respond in the way that they do. She points out that though Hacking talks of the person/subject/self/soul interchangeably, his focus is their interactions, not them, and therefore he does not 'delve into *what* it is about that self that is prone to being made up' (emphasis in original).³¹⁹ In other words, how uniform is the pattern of looping?- what factors make a person more or less likely to react in a certain way to their classification?- why are some people presented as pliable and suggestable but others seem more robust? In essence, 'what motivates changes in self-concepts and behaviour?'³²⁰ I think these are all serious questions that Hacking does not address.

In her analysis of the second unexplained aspect of the looping effect, Tekin focus-

³¹⁹ Tekin, S. 2014, p. 232.

³²⁰ Ibid., p. 238.

es on psychopathology, and the varying weight we should give to its different axis – classification, subjective symptoms, knowledge about diagnosis etc. She is right to point out that the relationship between these different factors is not adequately examined by Hacking. Three questions, says Tekin, remain:

- How much of the changes in the subject's self-awareness and behaviour are connected to the knowledge she receives about the diagnosis?
- How much of such changes are connected to her particular mental disorder?
- How much of the changes in her self-concept and behaviour are connected to the clinical treatment she receives upon diagnosis?

In short, she is arguing that in cases of psychopathology, and I would posit other conditions as well, the looping effect is not just mediated by the knowledge received by the patient about their classification, but also by their clinical encounters and the actual course of their illness. That Hacking fails to elucidate and situate these other potential influences in detail is a weakness of his approach. I would add one further question to Tekin's three:

- How much does the immediate social environment of an individual alter their self-concept?

Hacking has already discussed how the 'larger human unit' that surrounds an autistic child or other inaccessible kind can influence looping, but I think he underestimates the impact that family, social and workplace environments can have on a person's relationship to their category and themselves. Partly this is due to intellectual positioning. Though he acknowledges his debt to both, to me Hacking is clearly further towards Foucault's top-down, institutional study of meanings than

Goffman's bottom-up approach. He is, I think, instinctively more interested in how large, organising bodies of epistemic production affect individuals under their gaze than how interpersonal relationships with others might produce similar effects. This could just be because he is a philosopher and not a sociologist, and because using Foucauldian methods have a tendency to produce Foucauldian results.³²¹ It may be in fact that it is a several step process, where the first arc of looping is indeed directed by institutions and social scientists. But I would posit that after this stage the direction of such loops becomes muddied. Other members of society, not in the group themselves but aware of its classification, may come to have a more important role in generating feedback relationships. Goffman wrote about this in *The Insanity of Place*.³²² This work represented a shift in focus from the more institutional, closed-system type analysis of *Asylums* towards an intimate and probably highly autobiographical account of illness in a family setting.³²³ He recognised the immense power of feedback within an immediate social setting and how it might slot in with other factors such as diagnosis and institutionalisation. Hacking does, on the face of it, acknowledge the potential relevance of such an intersection:

'Goffman's idea of looping applies to one rather well-understood phenomenon of face-to-face interaction. Mine, much less well understood, applies to a quite different phenomenon bearing on classification itself. Yet it is very probably that my kind of looping, at the abstract level of discourse, works only because of Goffman's

³²¹ 'As a research strategy, I have always been much taken by what Michel Foucault named archaeology. I think that there are sometimes fairly sharp mutations in systems of thought and that these redistributions of ideas establish what later seems inevitable, unquestionable, necessary', in Hacking, I. 2002, p. 4.

³²² Goffman, E. 'The Insanity of Place' in *Psychiatry: Journal of Interpersonal Relations*, 1969, Vol. 32, No. 4, pp. 357-387.

³²³ Shalin, D. N. 'Goffman on Mental Illness: *Asylums* and "The Insanity of Place" Revisited' in *Symbolic Interaction*, 2014, Vol. 37, No. 1, p. 128; Goffman, E. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, 1961, Doubleday Anchor, USA.

concrete looping effect, at the interpersonal level of face-to-face interaction'³²⁴

I would say that this is incorrect, or at least incomplete. What Hacking is arguing is that his looping effect is between the classification and the classified, that this is a dynamic relationship of change, and that this is perhaps sustained by face-to-face interaction. What I would argue is that once the ball is rolling, so to speak, it is often the wider social context of an individual, represented by constant interpersonal and now online encounters, which affects their relationship with their category.³²⁵ *This*, in some cases, causes more change, more 'movement' of the interactive kind, than anything else. Therefore, the broader social environment's reaction to the classification (and indeed the broader social environment's *understanding* of the classification) of the individual is what has caused the kind to shift and become something new, not their personal interactions with their category. Most crucially, subsequent changes in the institutional categorisation of an individual may well have little effect on the way they are classified socially, and thus may be of limited impact in relation to the dynamism of the interactive kind.

I do not think that it is controversial to emphasise the importance of this level of looping. Individual's identities are constituted and reconstituted continuously on the basis of our interactions with others. We come to think of our selves as being *this* way and not *that* way only within a social matrix, and it informs the way we interpret present and past events and actions. Some times we are even self-aware enough to realise that this process is occurring as it does so. In Doris Lessing's *The Golden Notebook*, for example, the narrator Anna Wolfe is also acutely aware of the impact that being part of one or other grouping can have on social relations. Anna

³²⁴ Hacking, I. 2004, p. 299.

³²⁵ Or, as Goffman writes 'the third parties, the patient's daily circles: his service community, his work place, his friendships and particularly his family' in Goffman, E. 1969, p. 360.

describes an encounter with an old friend after she had joined the Communist party:

‘The fact I had become a party member, made me, for her, an embodiment of something she had to have certain attitudes towards. And I responded in kind. At which Michael said: ‘Well, what did you expect?’ He was speaking in his role of East European exile, to me in my role as ‘political innocent’. And I replied in that role, producing all sorts of liberal inanities. Fascinating – the roles we play, the way we play parts’.

It is fairly obvious what Anna (or perhaps Doris) is getting at here, that our categories change not just how we see ourselves but how the whole world sees us, which in turn alters how we view our identity and how we act. And I believe that this line of thought – that the social environment can become paramount in looping – has gained particular salience given the events of the decade or so since Hacking stopped writing substantially on this topic. In 1996 he wrote that ‘there has been a bizarre proliferation of self-help groups of late. Their core feature has been self-ascription: their rhetoric is that of taking control of themselves’.³²⁶

I would argue that due to a number of factors, most notably the internet’s galvanising effect on communication and the influence of individualist, identity-based movements, self-ascription is in many cases now the norm.³²⁷ In the case of contested illnesses, disease identities have been continuously fought over and negotiated at the theoretical level, and though they are still a case-study in uncertainty and diagnostic ambiguity, a sufficiently acceptable conceptual framework for several

³²⁶ Hacking, I. 1996, p. 379.

³²⁷ A process which has by now been occurring for decades. See: Franck, T. M. *The Empowered Self: Law and Society in an Age of Individualism*, 2000, Oxford University Press, UK.

diseases has been established.

Patients in many cases now have little conflict with their insitutional category (relatively speaking) because of the variety of meanings that are available and because of the hand they play in shaping those meanings themselves. The greatest source of tension that has evolved is not between classifiers and classified, because to some extent these have become one and the same, but between the classified and everyone else. These 'others', for whom the category means one thing or another (normally, in the eyes of patients, a retrograde and pejorative set of assumptions), are the boundary at which individuals react most to their grouping. It is these relationships we will look at in detail in the final chapter.

Chapter IV - Fibromyalgia in Context

At the beginning of this thesis, I explained that my aim was to examine chronic, contested disease in a philosophical context, or rather, in *its* philosophical context. To do this I have so far talked in general terms, stretching and teasing at the edge of concepts to test their robustness, and have outlined a number of overlapping frameworks that might aide our understanding of the experiences patients have. It is these experiences around which this chapter is based, the idea being to focus on the specific problems faced and language used by patients to test not only the ideas engaged with in previous chapters but also to look for gaps and things unsaid, to search through the speech of those with these conditions for the contours of what might loosely be termed ‘our general understanding of disease’ or the ‘prevailing notions of legitimate illness’.³²⁸

This is important as it links into all sorts of other epistemic points I wish to make - that the reality of disease for many people is greatly affected not just by ‘medical’ knowledge (in so far as it is possible to bracket this), but by the underlying meta-physical beliefs of the population at large and more specifically the population around the diseased person: their family, friends, work colleagues and indeed to a great degree themselves.³²⁹ In the same way that phenomenological work on illness has exposed the various physical aspects of our environment that we take for

³²⁸ This is a departure from the illness narrative literature that has taught me much: I am indeed, to use Riessman’s phrase, interested in ‘coding’ - that is, looking for particular items or topics - the patient speech I have recorded, but doing so in a way which takes into account the narrative context in which such remarks are made. My categories are porous not discrete, and I utilise narrative structure to illustrate points as well as short quotations from patients. (‘This approach does not fragment the text into discrete categories for coding purposes’ from Riessman, C. K. ‘Strategic uses of narrative in the presentation of self and illness: a research note’ in *Social Science and Medicine*, 1990, Vol. 30, No.11, p. 1195); for a full description of my methodology, see Appendix I.

³²⁹ This is not to say that the medical angle is unimportant, unrelated or will be glossed over in this chapter.

granted, I would like to chip away at our understanding of disease and uncover the presumptions, the intuitions, the expectations that shape our view of an ill person in our vicinity or in the mirror.³³⁰

In this chapter I will relate the content of my qualitative interviews with patients suffering from fibromyalgia, a complex and confusing disease which presents a serious challenge to health care providers and patients. I have split my findings into four broad categories: pain, relationships, work and care. These groupings are simply used to organise the disparate topics of conversation that patients discussed with me into something more easily analysed. In this final section I will bring to bear the various concepts discussed in Chapter I, use patient experience to bolster arguments made in Chapter II, test the ideas put forward in Chapter III and relate their thoughts to my general argument. First, though, I will present a short outline of the disease and use three examples from my research to illuminate some of the typical and nontypical features of the condition.

Fibromyalgia

Fibromyalgia is characterised by widespread musculoskeletal pain across the body, fatigue, cognitive issues and other symptoms. Patients are often co-morbid with a range of psychological conditions like depression and anxiety as well as other contested illnesses such as chronic fatigue syndrome and irritable bowel syndrome. Its aetiology is a site of conflict and no one model exists which can adequately map the disease. Likewise, the diagnostic tools used to demarcate the condition are also called into question.

As with many of the ailments it is often placed alongside, fibromyalgia has a trou-

³³⁰ Many years of disabilities rights activism have also worked hard to highlight the ‘able-bodiedness’ of our designed environments.

bled and oblique genealogy.³³¹ For those prone to scour history, confirmation bias in hand, examples of chronic pain, muscular discomfort and fatigue stretch from the Bible to Shakespeare.³³² These are of less interest to us, however, than the modern, explicitly diagnostic attempts to classify what remains an uncertain symptom constellation.

Although discussion of rheumatism, muscle sensitivity and tenderness can be found among physicians throughout the 19th century, the first reference to ‘fibrositis’ seems to appear in 1904, as used by Sir William Gowers. He hypothesised that an unknown process which inflamed the fibres of the lumbar muscles was the cause of backache.³³³ A contemporary physician of his named Ralph Stockman used the term more broadly to describe patients with symptoms that align quite isomorphically with modern presentation (stiffness and aching, muscular fatigue, general pain), and throughout the 20th century these vague complaints were variously swallowed by a number of diffuse classificatory frameworks, patients being assigned different labels and finding themselves under the care of various spe-

³³¹ For a far more exhaustive history of the concept than is presented here, see Inanici, F. and Yunus, M. B. ‘History of Fibromyalgia: Past to Present’ in *Current Pain and Headache Reports*, 2004, Vol. 8, pp. 369-378.

³³² The theatre would appear a particular rich source for such retrospective diagnosis, for example: Huth, K. ‘Figures of Pain in Early Modern English Tragedy’ in *Renaissance Drama*, 2014, Vol. 42, No. 2, pp. 169-190; I am thinking in particular of some Old Testament suffering: ‘...the days of affliction have taken hold upon me. My bones are pierced in me in the night season: and my sinews take no rest’. (Job 30: 16-17) or ‘Behold ye and see if there be any pain unto my pain, which is done unto me, wherewith the Lord hath afflicted me in the day of his fierce anger. From above hath sent fire into my bones...and I am weary and faint all the day’. (Jeremiah, in Lamentations 1: 12-13). This comparison is from Wallace, D. J. and Clauw, D. J. *Fibromyalgia and Other Central Pain Syndromes*, 2005, Lippincott Williams and Wilkins, USA, p. 1.

³³³ Malleon, A. *Whiplash and Other Useful Illnesses*, McGill-Queen’s University Press, Canada, 2002.

cialisms.³³⁴

It was not until the 1970s that ‘fibrositis’ again caught the the sustained attention of rheumatologists and began to stimulate clinical interest, leading directly to the dissemination of the diagnostic criteria that brought ‘fibromyalgia’ into existence.³³⁵ This began with Smythe, who sketched an outline of the condition which included much of what we now take to be of central importance: generalised muscle pain, fatigue, disrupted and low-quality sleep, aggravation through exertion, potential underlying emotional distress and multiple tender points.³³⁶ Further work was completed which emphasised the role that disturbed and unusual sleep patterns played in the aggravation of symptoms, and by 1983 key researchers were calling upon the field of rheumatology to produce reliable diagnostic criteria which could be used to accurately classify the disease now known as ‘fibromyalgia’.³³⁷ This was provided in 1990 by the American College of Rheumatology (ACR), who placed the presence of eleven (or more) out of eighteen possible ‘tender points’ at the centre of distinguishing between fibromyalgia patients and those with other conditions, these providing the ‘most discriminating power’,

³³⁴ Myofascial syndrome, neurasthenia, post-infectious fatigue, myasthenic syndrome, myalgic encephalomyelitis, myofasciitis and muscular rheumatism, for example.

³³⁵ Goldenberg, D. L. *Clinical Management of Fibromyalgia*, 2009, Professional Communications, pp. 12-13.

³³⁶ Smythe, H. ‘Nonarticular rheumatism and psychogenic musculoskeletal syndromes’ in McCarty, D. J. (ed.) *Arthritis and Allied Conditions*, 1972, Lea and Febiger, USA, pp. 881-891.

³³⁷ Moldofsky, H., Scarisbrick, P., England, R. and Smythe, H. ‘Musculoskeletal symptoms and non-REM sleep disturbance in patients with “fibrositis” syndrome’ in *Bulletin on the Rheumatological Diseases*, 1977-78, Vol. 28, pp. 928-931; Yunus, M. B., ‘Fibromyalgia: a need for uniform classification’ in *The Journal of Rheumatology*, 1983, Vol. 10, pp. 841-844; Hench was the first to use the term ‘fibromyalgia’ in Hench, P. K. ‘Nonarticular rheumatism, 22nd rheumatism review: review of the American and English literature for the years 1973 and 1974’ in *Arthritis and Rheumatism*, 1976, Vol. 19, pp. 1081-1089.

alongside widespread pain.³³⁸

Subsequent to this, research interest increased alongside rising patient numbers. It was clear that fibromyalgia patients presented with far more than simply tender points, and that the routine diagnostic test proposed by the 1990 criteria was rarely being used or was being used incorrectly. As a result, fibromyalgia became regarded as a ‘dustbin diagnosis’ or diagnosis of exclusion, a label given to patients when all other diagnostic options had been exhausted.

Though the ACR criteria stimulated plenty of research, along genetic, epidemiological, haematological and more general pathophysiological lines, this failed to translate into effective clinical practice, where diagnosis remained uncertain, treatment inconsistent and outcomes poor. In light of these problems, the ACR revised their criteria in 2010, introducing the use of widespread pain index (WPI) and symptom severity scale (SS) scores alongside a requirement that symptoms be present for at least three months or more and the presence of no other disorders which might better explain the symptoms.³³⁹

The current clinical picture is as follows.³⁴⁰ Fibromyalgia, or fibromyalgia syndrome as it is often referred, is characterised by widely distributed, chronic musculoskeletal pain, as well as elements of fatigue, joint stiffness, cognitive difficulty, sleep disturbances, headaches, bowel problems and other symptoms. The pain is

³³⁸ Wolfe, F., Smythe H. A. and Yunus, M. B. ‘The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia: report of the Multicenter Criteria Committee’ in *Arthritis and Rheumatism*, 1990, Vol. 33, pp. 160-172.

³³⁹ Wolfe, F. *et al* ‘The American College of Rheumatology Preliminary Diagnostic Criteria for Fibromyalgia and Measurement of Symptom Severity in *Arthritis Care and Research*, 2010, Vol. 62, No. 5, pp. 600-610.

³⁴⁰ This section is drawn largely from the following papers: Chinn, S., Caldwell, W. and Gritsenko, K. ‘Fibromyalgia Pathogenesis and Treatment Options Update’ in *Current Pain and Headache Reports*, 2016, Vol. 20 p. 25; Clauw, D. J. ‘Fibromyalgia: A Clinical Review’ in *The Journal of the American Medical Association*, 2014, Vol. 311, No. 154, pp. 1547-1555 and Bellato, E. *et al* ‘Fibromyalgia Syndrome: Etiology, Pathogenesis, Diagnosis, and Treatment’ in *Pain Research and Treatment*, Vol. 2012, Article ID 426130, pp. 1-17.

often variable and patients report that the intensity of their symptoms appears to be related to stress and physical exercise. Common patient conceptualisations of their symptoms include ‘fibrofog’, which is the inability to remember pieces of information, the clouding of an otherwise functional mind, and ‘flare ups’ which refer to a particularly bad symptomatic reaction to something, such as stress, physical overexertion or changes in the weather.³⁴¹

As might be expected from these symptoms, fibromyalgia patients suffer from considerable psychosocial impairment and a reduced - in some patients absolutely - ability to work. They also represent a considerable cost to their respective health services as repeat appointments, referrals, hospital admissions, multiple prescriptions and various other therapies are required.

Depending on the diagnostic method employed, prevalence varies from between 1.3-8% and is most common among middle aged women.³⁴² Fibromyalgia is estimated to be between twice and four times as prevalent in females as in males, though it had been reported that in some societies this ratio is even greater.³⁴³ Sev-

³⁴¹ The link with weather appears to be widespread amongst patients but disputed by researchers. See Bossema, E. R. *et al* ‘Influence of Weather on Daily Symptoms of Pain and Fatigue in Female Patients With Fibromyalgia: A Multilevel Regression Analysis’ in *Arthritis Care and Research*, 2013, Vol. 65, No. 7, pp. 1019-1025.

³⁴² Smith, H. S., Harris, R. E., Clauw, D. J. ‘Fibromyalgia’ in Benzoni, H. T., Raja S. N., Moll, R. E., Liu, S. S., Fishman, S. M. (eds.) *Essentials of pain medicine*, 2011, 3rd ed., Elsevier, USA, pp. 345–350; Theoharides, T. C., Tsilioni, I., Arbetman, L. *et al* ‘Fibromyalgia syndrome in need of effective treatments’ in *The Journal of Pharmacology and Experimental Therapeutics*, 2015, Vol. 355, pp. 255–263; Diaz-Piedra, C., Di Stasi, L. L., Baldwin, C. M., Buena-Casal, G., Catena A. ‘Sleep disturbances of adult women suffering from fibromyalgia: a systematic review of observational studies’ in *Sleep Medicine Reviews*, 2015, Vol. 21, pp. 86–99.

³⁴³ Branco, J. C. *et al* ‘Prevalence of fibromyalgia: a survey in five European countries’ in *Seminars in Arthritis and Rheumatism*, 2010, Vol. 39, No. 6, pp. 448-53; Lindell, L., Bergman, S., Petersson, I. F., Jacobsson, L. T. H., and Herrstrom, P. ‘Prevalence of fibromyalgia and chronic widespread pain’ in *Scandinavian Journal of Primary Health Care*, 2000, Vol. 18, No. 3, pp. 149–153; for example, a Danish source put the gender split at 1:9: see Bartels E. M. ‘Fibromyalgia, diagnosis and prevalence. Are gender differences explainable?’ in *Ugeskrift for Læger*, 2009, Vol. 171, No. 49, pp. 3588-92.

eral epidemiological meta-analyses have demonstrated that fibromyalgia is present on every inhabited continent, with inter-country variations ascribed to different clinical attitudes, application of diagnosis and patient behaviour.³⁴⁴

Co-morbidity with other ‘functional’ (and ‘contested’) illnesses is high and it is common for a fibromyalgia patient to suffer from one or several of the following: chronic fatigue syndrome, irritable bowel syndrome, depression, anxiety, migraine headaches, obsessive compulsive disorder and others, including many multiple non-specific symptoms.³⁴⁵ In some study populations it has been found that more than half of fibromyalgia patients have seven or more chronic co-morbidities.³⁴⁶

The aetiology and pathogenesis of fibromyalgia remains poorly understood, but it is posited that some combination of genetics, central and automatic nervous system dysfunction, neurotransmitters, hormones, immune system deficiencies, external trauma, environmental factors and psychiatric problems are involved. No one, definitive aetiological narrative has been established and as yet no consistent enough biomarker has been discovered that can indicate and demarcate fi-

³⁴⁴ Queiroz, L. P. ‘Worldwide Epidemiology of Fibromyalgia’ in *Current Pain and Headache Reports*, 2013, Vol. 17, No. 356; Neumann, L., and Buskila, D. ‘Epidemiology of Fibromyalgia’ in *Current Pain and Headache Reports*, 2003, Vol. 7, pp. 362-368.

³⁴⁵ Goldenberg, D. L. *et al* ‘Understanding Fibromyalgia and Its Related Disorders’ in *The Primary Care Companion To The Journal Of Clinical Psychiatry*, 2008, Vol. 10, No. 2, pp. 133-144; Arnold, L. M., Hudson, J. L., Keck, P. E., Auchenbach, M. B., Javaras, K. N. and Hess, E. V. ‘Comorbidity of fibromyalgia and psychiatric disorders’ in *The Journal of Clinical Psychiatry*, 2006, Vol. 67, No. 8, pp. 1219-25.

³⁴⁶ Vincent, A., Whipple, M. O. and McAllister, S. J. *et al* ‘A cross-sectional assessment of the prevalence of multiple chronic conditions and medication use in a sample of community-dwelling adults with fibromyalgia in Olmsted County, Minnesota’ in *BMJ Open*, 2015, Vol. 5, e006681. doi:10.1136/bmjopen-2014-006681; This should be qualified by noting that, increasing as you go up the age scale, multiple co-morbidities are common (see: Piccirillo, J. F. *et al* ‘The Changing Prevalence of Comorbidity Across the Age Spectrum’ in *Critical Reviews in Oncology/Hematology*, 2008, Vol. 67, No. 2, pp. 124-132), so in this instance it might be sensible to consider the *quality* of the co-morbidities rather than their *quantity*.

bromyalgia with any reliability.³⁴⁷ As such, the diagnosis of fibromyalgia remains a process of elimination and subjective reporting, occasionally in tandem with the ACR criteria.

A major problem with identifying fibromyalgia is its similarity to other conditions, and patients are often told they suffer from a multitude. A literature review by Aaron and Buchwald highlighted this problem, noting that despite different case definitions, overlap between conditions appeared to be high:

‘The existing literature, although dispersed across many disciplines, suggests that many unexplained clinical conditions—for example, the chronic fatigue syndrome, fibromyalgia, and temporomandibular disorder—share demographic, clinical, and psychosocial features, as well as objective findings. In fact, it has been suggested that the diagnosis assigned to patients with one of these illnesses depends more on chief symptom and clinician specialty than on the actual illness’.³⁴⁸

Wessely, Sharpe and Nimnuan had previously argued along similar lines, that each medical speciality appeared to have its own ‘unexplained’ syndrome which, when examined as patient populations, would seem to overlap greatly in terms of both

³⁴⁷ Giacomelli, C., Sernissi, F., Rossi, A., Bombardieri, S. and Bazzichi, L. ‘Biomarkers in fibromyalgia: a review’ in *Current Biomarker Findings*, 2014, Vol. 4, pp. 35-41.

³⁴⁸ Aaron, L. A. and Buchwald, D. ‘A Review of the Evidence for Overlap among Unexplained Clinical Conditions’ in *The Annals of Internal Medicine*, 2001, Vol. 134, p. 868.

symptoms and treatment strategies.³⁴⁹ They concluded that the classificatory slicing of different functional somatic syndromes was of questionable utility, given the apparent lack of concrete delineating factors. In place of this, they suggested that a dimensional approach might work better, on the understanding that all present subdivisions are attempts to demarcate something which to a great degree is singular: general functional somatic syndrome.

Perhaps predictably, there was a strong reaction to this hypothesis among some members of certain patient communities, rejecting Wessely *et al*'s ideas and in some cases resorting to personal attacks and threats. This backlash illuminated another layer of complexity when regarding this issue: once given a diagnosis, sufferers can build up rationalities and explanatory frameworks with which to understand their condition and become in a sense loyal to these descriptions and unwilling to countenance an entirely new and less legitimate sounding disease that they now supposedly have or indeed had all along.³⁵⁰

There are, of course, a number of other ideas orbiting fibromyalgia. For example, Yunus and other rheumatologists are of the view that fibromyalgia is best conceptualised and classified as a central sensitivity syndrome (CSS).³⁵¹ This is where the

³⁴⁹ Wessely, S., Nimnuan, C. and Sharpe, M. 'Functional somatic syndromes: one or many?' in *Lancet*, 1999, Vol. 354, pp. 936-939; Incidentally, this paper sparked a debate (ongoing) between 'splitters' who believed in the usefulness of divergent diagnoses and 'lumpers' who argued for a broader category which acknowledged the wide overlap. For a recent summary of these arguments, see Lacourt, T., Houtveen, J. and van Doornen, L. "Functional somatic syndromes, one or many?": An answer by cluster analysis' in *The Journal of Psychosomatic Research*, 2013, Vol. 74, No. 1, pp. 6-11; It is for this reason - symptom similarity and overlap in populations - that in this section I draw on the chronic fatigue syndrome literature as readily as that of fibromyalgia.

³⁵⁰ Wessely, S. and White, P. D. 'In Debate: There is only one functional somatic syndrome' in *The British Journal of Psychiatry*, 2004, Vol. 185, No. 2, pp. 95-96.

³⁵¹ Yunus, M. B. 'The Prevalence of Fibromyalgia in Other Chronic Pain Conditions' in *Pain Research and Treatment*, 2011, No. 584573; Fleming, K. C., Volcheck, M. M. 'Central Sensitisation Syndrome and the Initial Evaluation of a Patient with Fibromyalgia: A Review' in *Rambam Maimonides Medical Journal*, 2015, Vol. 6, No. 2, e0020.

central nervous system exaggerates pain across different bodily systems and generates a number of debilitating symptoms as the body becomes hypersensitive to external stimuli.³⁵²

These researchers also take a hard line against the language that is used to describe fibromyalgia patients in other fields, and Yunus argues (as I do in Chapter I) against the firm division of ‘disease’ and ‘illness’ along biomedical lines:

‘...differentiation between illness and disease is artificial and contrary to patient interest and hampers proper management of CSS conditions, since anything that is not currently viewed as a disease (i.e., does not have structural pathology, e.g., inflammation, degeneration, or neoplasm) is viewed as predominantly or exclusively psychological and benign and is not taken seriously by the health care providers, accentuating the suffering of the patients. In an irresponsible way, this untruthful “dogma” is passed down from the professor or the attending to the students, and the victims are our patients’.³⁵³

Elsewhere he has stated:

‘Patient-blaming terms like somatization, somatizer and catastrophizing should be avoided’.³⁵⁴

³⁵² Hypersensitive in both the allodynic (pain from things which are ordinarily non-painful) and hyperalgesic (when mildly painful things are experienced as excruciating) senses.

³⁵³ Yunus, M. B. 2011, p. 1-2.

³⁵⁴ Yunus, M. B. ‘Editorial Review: An Update on Central Sensitivity Syndromes and the Issues of Nosology and Psychobiology’ in *Current Rheumatology Reviews*, 2015, Vol. 11, No. 2, pp. 70-85.

Regardless of the validity of their physiological explanations, and I don't think I am in a position to pass judgement on that, Yunus and others like him recognise a key truth: the way the medical cards are dealt, the cards are stacked against patients with contested illnesses. *Style matters*. The language employed does have strongly negative connotations and the prestige hierarchy of physical and psychological ailments is reinforced (intentionally or not) by its use. These writers are certainly correct to point this out, as well as to note that bracketing 'disease' in the manner that it is, excludes a whole range of conditions from ascending to bona fide disease status with deleterious consequences for the patients involved.

As might be expected, these thoughts are not echoed by all practitioners. Hadler states firmly that he believes this to be the wrong approach, dismissing central sensitisation specifically as a 'contrived neologism'.³⁵⁵ The problems faced by patients are largely iatrogenic, he argues, caused by 'treatment acts, dripping with empty promises of elucidation and unproved promises of palliation'.³⁵⁶ Indeed, Hadler believes that telling patients they suffer from a distinct and diagnosable condition called fibromyalgia amounts to the clinically irresponsible 'medicalisation of misery' and he is not alone in that, or similar, views.³⁵⁷

Wolfe, for instance, believes that the controversy surrounding fibromyalgia (what he terms the 'fibromyalgia wars') is 'best understood in terms of medicalisation and social construction'.³⁵⁸ In a later paper, he outlines his position as follows:

³⁵⁵ Hadler, N. M. 'Editorial: "Fibromyalgia" and the Medicalisation of Misery' in *The Journal of Rheumatology*, 2003, Vol. 30, No. 8, p. 1669.

³⁵⁶ *Ibid.*

³⁵⁷ *Ibid.*, p. 1668; Ehrlich, G. E. 'Pain is real; fibromyalgia isn't' in *The Journal of Rheumatology*, 2003, Vol. 30, No. 8, pp. 1666-1667; for responses to these viewpoints, which further illustrate the range of opinions held see 'Letters' in *The Journal of Rheumatology*, 2004, Vol. 31, No. 4, pp. 827-829.

³⁵⁸ Wolfe, F. 'Fibromyalgia wars' in *The Journal of Rheumatology*, 2009, Vol. 36, pp. 671-678.

‘There is as yet no compelling evidence that an underlying central nervous system disturbance contributes in a substantial or clinically meaningful way to the development of fibromyalgia. In addition, neurobiological associations depend on fibromyalgia being a discrete disorder, for which no evidence exists. Even if fibromyalgia is considered to be largely a psychocultural disorder, a strong body of criticism suggests that the definition of fibromyalgia is arbitrary, and the methods of assessment illusory’.³⁵⁹

In other words, Wolfe and many doctors across rheumatology and other disciplines believe that fibromyalgia is not a separate clinical entity nor a useful diagnostic tool and its continued existence as a disease concept is largely the result of social factors and not any underlying medical reality. Furthermore, the insistence on labelling non-distinct, vague symptoms as if they were part of a cohesive whole has the effect of solidifying false illness beliefs, making patients sicker than they were before and impeding potentially effective treatment.

Malleson also takes this view, but frames his skepticism about fibromyalgia around ‘compensation neurosis’, the rise in injury payments and what he views as an unscrupulous welfare state that incentivises invalidity.³⁶⁰ He writes dryly that ‘rather than curing diseases, medicine is manufacturing new ones’.³⁶¹

Whether or not we should collect patients with seemingly disparate symptoms under one diagnostic label, or indeed under a series of diagnostic labels, is a difficult question to answer. I certainly have sympathy with those who question its validity

³⁵⁹ Wolfe, F. and Walitt, B. ‘Culture, science and the changing nature of fibromyalgia’ in *Nature Reviews Rheumatology*, 2013, Vol. 9, p. 751.

³⁶⁰ Malleson, A. 2002, pp. 165-196; for a description and analysis of ‘compensation neurosis’, see Hall, Ryan C. W. and Hall, Richard C. W. 2012, pp. 390-398.

³⁶¹ Malleson, A. 2002, p. 172.

as a medical approach. What I do take umbrage with, however, is the suggestion that the ‘solution’ to this patient population (however they may be composed) is to remove social security benefits and medical nomenclature. My disagreement stems from the fact that, as we shall see, many individuals receive neither welfare payments nor diagnosis for years, and yet their symptoms persist. These are patients for whom an eventual diagnosis comes as a surprise, and for whom the label ‘fibromyalgia’ is of limited utility; they are surprised because they were expecting something specific and physical - a viral infection, an autoimmune dysfunction - and underwhelmed because of the dearth of information available about fibromyalgia and its lack of cachet as a responsibility-absolving diagnosis.

Returning to professional perceptions, on the part of general practitioners and specialists who come into contact with fibromyalgia, survey data is scarce but it would appear to suggest that a majority support a psychosomatic view of the condition.³⁶² A small minority regard it as a ‘non-disease’ and some rheumatologists refuse to receive referrals or provide ongoing care for patients with the diagnosis.³⁶³ Evidence also shows that experienced doctors across a variety of countries lack confidence in diagnosing and treating fibromyalgia, especially in relation to making a differential diagnosis, and that that find fibromyalgia patients frustrating to

³⁶² A small study of rheumatologists in Canada reported that 55% believed fibromyalgia to be primarily psychosomatic rather than physiological: Ghazan-Shahi, S., Towheed, T. and Hopman, W. ‘Should rheumatologists retain ownership of fibromyalgia? A survey of Ontario rheumatologists’ in *Clinical Rheumatology*, 2012, Vol. 31, No. 8, pp. 1177-1181; another Canadian survey of different specialists reported the with regard to aetiology, 28% thought fibromyalgia was primarily psychological, 23%, primarily physiological, 15% psychological and physiological, and 34% were unsure: Busse, J. W., Kulkarni, A. V., Badwall, P. and Guyatt, G. H. ‘Attitudes towards fibromyalgia: A survey of Canadian chiropractic, naturopathic, physical therapy and occupational therapy students’ in *BMC Complementary and Alternative Medicine*, 2008, Vol. 8, No. 24, doi: 10.1186/1472-6882-8-24.

³⁶³ 8% of respondents to a BMJ survey regarded fibromyalgia as a ‘non-disease’: ‘What do you think is a non-disease?’ in *The British Medical Journal*, 2002, Vol. 324, p. 7334; Kraag, G. ‘Fibromyalgia’ in Mosher, D., Stein, H. and Kraag, G. (eds.) *Living well with arthritis*, 2002, Viking Press, Canada, pp. 55-64.

treat.³⁶⁴ A study by Album and Westin also suggested that doctors regard fibromyalgia as less ‘prestigious’ than other diseases, placing it bottom of a hierarchy of 38 conditions.³⁶⁵

I could go on, such is the multiplicity of opinion and clinician perspectives that exists on this topic (and indeed related topics), but endlessly mapping the various lines in the sand that have been drawn over the last few decades will simply serve to make the same point over and over again: fibromyalgia is a terribly convoluted and tangled affair.

It is inevitable, I surmise, that such an interwoven conflict of diagnostic reliability, clinical pragmatism and aetiological ambiguity will continue unless wholesale epistemic change is enacted across the medical world and conditions of this sort - subjective, symptomatic - come to be regarded as valid disease entities despite their

³⁶⁴ Perrot, S., Choy, E., Petersel, D., Ginovker, A. and Kramer, E. ‘Survey of physician experiences and perceptions about the diagnosis and treatment of fibromyalgia’ in *British Medical Council Health Services Research*, 2012, Vol. 12, No. 356, doi: 10.1186/1472-6963-12-356; this frustration stems in part from what doctors view as a damaging preoccupation with multiple, vague symptoms, as well as the perception amongst patients about the great impact of their condition upon their lives: Walker, E. A. *et al* ‘Predictors of physician frustration in the care of patients with rheumatological complaints’ in *General Hospital Psychiatry*, 1997, Vol. 19, No. 5, pp. 315-323; Homma, M., Ishikawa, H. and Kiuchi, T. ‘Association of physicians’ illness perception of fibromyalgia with frustration and resistance to accepting patients: a cross-sectional study’ in *Clinical Rheumatology*, 2016, Vol. 35, No. 4, pp. 1019-1027.

³⁶⁵ This ‘prestige hierarchy’ was arrived at as follows: ‘Respondents were asked to rank these 38 diseases and 23 specialities individually on a scale of 1 (lowest prestige) to 9 (highest prestige), based on how they believed most health personnel would rank them. The wording of the question was for the prestige of diseases (in translation): “Below you will find a list of 38 diseases or disease categories. Please give each disease a number based on the prestige you imagine it has among health personnel. A disease you feel is considered to have a low prestige should be given a low number, the lower the prestige, the lower the number. Oppositely, a disease you feel have a high prestige should be given a high number, the higher the prestige, the higher the number. Please circle the number you choose”’; Album, D., and Westin, S. 2008, pp. 182-188.

clear incompatibility with biomedical methods of ratification.³⁶⁶ Should this change not be forthcoming, and the evidence is that it is slow to do so, then undoubtedly such conflicts will continue.

What is likely then, is that patients will continue to meet a range of reactions in both the clinic and on the street. There being, as described above, no completely or even partially established ‘medical’ view, the response that patients receive can be incredibly diverse. The most damaging of these from the patient’s perspective is that of disbelief or suspicion. As Harth has written:

‘...patients with fibromyalgia have to shoulder a burden seldom borne by individuals with other medical conditions. Fibromyalgia sufferers are frequently not perceived as having a distressing condition...patients with fibromyalgia seeking help from their physicians may encounter hostility, skepticism, confusion and therapeutic nihilism’.³⁶⁷

Harth also notes that ‘their families, their friends and their coworkers are often sceptical of their symptoms or their functional impairment’.³⁶⁸ This atmosphere of disbelief and the discrediting of an individual as a producer and communicator of knowledge has been analysed from an epistemic perspective by a number of au-

³⁶⁶ Or, it should be noted, unless the conditions in question can be more successfully assimilated into biomedical structures through the discovery of some pathogen or other physiological process.

³⁶⁷ Harth, M. ‘Cursing the darkness: Reactions to fibromyalgia’ in *Pain Research and Management*, 2013, Vol. 18, No. 2, p. 64.

³⁶⁸ *Ibid.*

thors, most notably Fricker, under the banner of ‘epistemic injustice’.³⁶⁹ This, by now a multifarious concept in possession of various subdivisions, can for our purposes here be simplified: it is a state in which a speaker’s credibility is diminished or erased due largely to prejudice on the part of the listener. Lying at the juncture of epistemology and ethics, epistemic injustice can be used to understand how communication can be stacked for and against certain parties, and the damage that can arise from such arrangements.

Originally, this concept was used to bring attention to the ways in which the gender and race of the speaker, among other irreducible features of a person’s identity, might lead to the systematic devaluing of their perspective and the discounting of any epistemic contributions an individual thought or was required to make in a given situation. Recently, however, it has been expanded and applied to medical contexts.

Carel, Blease, Kidd and others have argued that it is especially applicable in healthcare settings, both in regard to the doctor/patient dynamic (the ‘encounter’) and also to broader issues of medical training and policymaking.³⁷⁰ Epistemic injustice can result not only in bad interpersonal relations (no-one enjoys being patronised or ignored), but also in the missing or misinterpreting of key information because the epistemically privileged individual has chosen to interpret the experiences of another entirely through a framework that undermines the credibility of the patient’s communication. What is of relevance to our discussion here is the

³⁶⁹ Note that Fricker does not explore the medical aspect of epistemic injustice: Fricker, M. *Epistemic Injustice: Power and the ethics of knowing*, 2007, Oxford University Press, UK; see also Hookway, C. ‘Some varieties of epistemic injustice: response to Fricker’ in *Episteme*, 2010, Vol. 7, pp. 151-163 and Coady, D. ‘Two concepts of epistemic injustice’ in *Episteme*, 2010, Vol. 7, pp. 101-113.

³⁷⁰ Blease, C., Carel, H. and Geraghty, K. ‘Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome’ in *The Journal of Medical Ethics*, 2016, Vol. 0, pp. 1-9, doi: 10.1136/medethics-2016-103691; Kidd, I. J. and Carel, H. ‘Epistemic Injustice and Illness’ in *The Journal of Applied Philosophy*, 2017, Vol. 34, No. 2, doi: 10.1111/japp.12172.

ways in which patients with contested illnesses experience and deal with epistemic injustice and how this comes to pass.

What should be evident by now, and certainly will be evident by the end of this chapter, is that the fibromyalgia patient reporting debilitating pain is not afforded the same epistemic status as an individual with, say, gallstone problems would be.³⁷¹ That this occurs both in the clinical context and outside, and that it can fluctuate over time in relation to external events ('belief turns to disbelief as when tests come back normal'), is of great interest to us here.³⁷² Routinely, as we shall see, their self-reporting of symptoms and pleas for sympathy are filtered by doctors and those around them in a manner which diminishes their severity and shifts the moral onus from external dysfunction to individual responsibility once it becomes apparent that their problems stem from fibromyalgia rather than some other, more acceptable source.

It is this, the broad *reaction* to fibromyalgia and all its attendant consequences for individual patients, that will be the focus of this chapter. In order to flesh out or bring to life some of the conflicts and confusions discussed above, I will present the experiences of three patients I interviewed. The variation present in their stories will hopefully elucidate some of the more tricky aspects of this subject: their symptoms, the meanings they are given by themselves and others, the bureaucratic and medical pillar-to-posting involved, the compromised and transformed sense of self and surroundings...these can all be seen most starkly when shown through the lives of real patients. In the following section I present three illuminative patient profiles, drawn from my semi-structured interviews with the patient community.

³⁷¹ This particular form of epistemic injustice is referred to as 'testimonial'.

³⁷² The quote is from the movie *Voices from the shadows*, directed by Josh Biggs and Natalie Boulton, also used as an example by Carel in Carel, H. 2016b, p. 186.

Three patients

Lucy worked for twenty five years for what was the Department for Social Security and is now the Department for Work and Pensions in a job centre before she was forced to leave due to ill health.³⁷³ Initially, she had been to see her doctor about some lower back pain, but the scans they completed came back negative. Following this, her wrists and hands began to hurt and the doctors suspected that she might have RSI. Then:

‘...other bits started aching and being problematic and I was going in quite a lot. The doctors thought it was in my head, that it was depression, that I was feeling low which I wasn’t. I was just getting fed up with not being able to do things’.

Prior to these complaints, Lucy had led an active life, playing sports and exercising frequently. She felt frustrated by the increasing limitations that her mysterious symptoms were placing her under. Eventually she got a diagnosis:

‘I was referred to a chronic pain consultant and he was the one who said it was fibromyalgia, which I’d never heard of. All the key points were hurting and the symptoms fitted in with that. He pieced everything together’.

Having a name to put to her symptoms allowed Lucy to conduct research, and past events began to congeal into a coherent illness narrative for her. Recounting her personal history, she placed salience on two traumatic events that occurred within quick succession of each other: a bad car accident that required treatment and divorce from her husband. Lucy now believes that within nine months of these

³⁷³ All names have been changed. See Methodology for details.

things happening she began to develop pain across her body. The pain itself is bad but she has found ways to manage it. If she has a flare up, it can take a while for the worsened symptoms to return to normal, and though they never leave her entirely, she has developed coping mechanisms which she tries to employ as diligently as possible. Still, it is often a case of simply ‘muddling’ through.

Since her diagnosis, Lucy’s experiences with doctors have not been overly positive. Largely she has found GPs to be unsympathetic, treating her as if she is wasting their time and occasionally appearing to induce guilt on her behalf because of the expense of long-term treatment:

‘A GP called me in to up my medication but purely on the basis that it was around twenty pound a box cheaper than the medication I was on. He went through the cost of it and how much I was costing the surgery. You feel like a drain on their resources and blooming angry as well. I didn’t actually want to increase my medication but you’re just kind of thrown into it’.

Feeling pressured in this way was not the only poor communication Lucy had with her doctors. In other instances she struggled to get them to appreciate that she felt she knew her body well enough to act as a competent translator:

‘You have to prove yourself all the time and say well yes, this really does hurt. Especially when they say it’s depression. I’ve suffered from depression in the past, I know what it’s like and no, *this* is a pain, it’s really hurting me. I’ve had other pains that aren’t fibro and I told him it wasn’t the same but he said “we’ll add another tablet in, it must be the fibro”. Trying to distinguish and tell them that no, it’s something different, is met with the cop-out that it must all be fibro, off you go, you’ll be fine. People just aren’t listening to what you’re saying and you’re just la-

belled as someone with chronic pain symptoms’.

The GP surgery is not the sole location that Lucy found it difficult to get the way that she was feeling across to a professional in a manner that she deemed acceptable. After trying and failing to find further, more flexible employment, she found herself back at the job centre she had left due to sickness, for a disability assessment. She felt that throughout her appraisal she was made to feel as if they regarded her condition as one which could be alleviated through willpower:

‘The chap I saw there went on about people who have lost their limbs and how they use their mind to get rid of the phantom limb pain and that. He was sort of implying that it was all in my head and that I should be able to use my mind to control all of these pains. It wasn’t until I burst into tears and argued back about fibro that he changed his opinion. He still put fibro in inverted commas as if it wasn’t a real illness though, which did rather annoy me’.

In what will become a reoccurring motif in this chapter, Lucy bristles at the suggestion that her symptoms are in her head - that is to say controllable, somehow invented.³⁷⁴ She recounts lying in bed, crying in pain and wishing that those people who doubt her could see her, so that they can see the evident distress she is in. ‘You try living with this’, she says to these people, ‘I’m not making it up’.

Despite this anger at her treatment and desire for greater recognition of her discomfort, Lucy tries to maintain a positive outlook, and believes that this assists her

³⁷⁴ There is perhaps some confusion on this point. When medical professions use the terms ‘all in your head’ or similar, they may well mean to say that the pain is real and that, though the cause is psychological rather than physiological, the patient bears no responsibility for it. However, this is not the way such statements are interpreted by patients, who receive the message as if they have been accused of having agency in relation to their symptoms.

in dealing with her symptoms:

‘I could be miserable every day if I wanted to be. It doesn’t do anyone any help. It doesn’t help me to be miserable and dwell on things so that’s why I don’t want to. It’s very easy to be depressed when you’re feeling that, really, half of your life has gone and that the person you were before has disappeared. I just want to get on with trying to cope with it’.

It is this attitude that she takes with her into a local fibromyalgia support group, of which she is treasurer. Here, too, they try not to dwell and rather focus on sharing palliative solutions and organising events to raise money. Lucy is simultaneously resigned to her fate and taking regular steps to alleviate it, a common bind for chronically ill patients. She doesn’t fear that it is fatal, has her own understanding of what the disease means and has altered her life as much as possible to cope with the disjunction it has caused. Samuel’s story is quite different.

His symptoms have a distinct starting point. He was attacked from behind in the street in an unprovoked assault. Samuel told me he was ‘lucky enough’ to pass out quickly, but later was shown CCTV of the attackers striking his head with bottles until they smashed. He was admitted to hospital that night, his ‘nose broke, bed covered in blood’. Despite this, when his wife came to see him he checked himself out, not realising the severity of his condition. Within a week he noticed a dramatic deterioration in his motor skills and found himself unable to complete simple tasks like opening the door of his car. Further tests revealed a massive blood clot, and doctors sought permission from Samuel to write up his case in a journal as they had never before seen such a large clot in that area of the brain in someone still alive. It was successfully removed, but this was not the end of Samuel’s problems.

Initially it seemed as if he was on track to make a full recovery. He was able to get a job as a support worker in social care, helping young people with behavioural problems, and he tried to put the attack behind him. In time, however, his symptoms did not disappear but rather began to multiply and worsen. He would get spasms down the left hand side of his spine and at the top of his neck, pains in his legs, was 'fatigued all the time, constantly tired' and 'never seemed to get a proper sleep'. Often, he would 'wake up half an hour after going to sleep, in a cold sweat'. Seizures and memory problems became a reality of daily life that Samuel had to adjust to.

He found the response from the GP unhelpful. They prescribed painkillers, building and diversifying the dose until he felt that his house was 'like a chemist' but doing little to alleviate his symptoms. 'All they do is give you tablets', he said, 'medicate, medicate, medicate'. The problems he reported were also met with scepticism:

'My GP told me that if I ignored it it would go away. And that they didn't believe in fibromyalgia. I said "well, the pain I'm in...I'm not imagining the pain". I wasn't getting anywhere with him and it was really depressing me. I'm in so much pain and the doctors were telling me to just ignore it'.

It became hard at times for Samuel to distinguish between which symptoms were emanating from his body and which were being induced by the significant amount of medication he was taking. Night tremors interrupted his sleep even more and he became increasingly light-sensitive and resorted to keeping the blinds down in his house so that he could get some relief. In response to the latter of these problems, he now wears glasses with an anti-glare coating to afford him a little respite from bright light. Both of these symptoms he initially put down to the drugs he had been prescribed, but finds it understandably difficult to untangle causality in a

body so racked by strange symptoms and ingesting so many painkillers.

He also started having frequent seizures. The following situation might make clear the frightening and disorienting nature of Samuel's condition:

'I was in the house when I woke up and I was covered in sweat and I don't know if I'd had a seizure or what happened but I'd run up the stairs to the toilet and the next thing I know I'd woke up on the floor and I'd banged my head and I had massive lumps on both sides. I had a temperature but I don't know how it happened. I'd also urinated when I'd collapsed up the stairs'.

Whilst at work he suffered another seizure and had to take a fortnight off, during which time he remained mostly on the sofa, only rising to use the bathroom. His symptoms during this time accord with what many fibromyalgia patients refer to as a 'flare up': his 'muscles were agony all over...like [he'd] been beaten'. He was able to return to work but lost his driving licence as a result of the seizure.

This was to prove costly, as his employment then deemed him to have frustrated his contract as a result of becoming unable to drive. Not able to work, at least in the short term, he decided to apply for a Personal Independence Payment, which involved an hour and a half drive to the nearest centre:

'My wife was taking me. They were asking me questions like, "how did you get here?"', to which I said, "my wife drove me". Then asking me if I could count, asking me to spell things backwards. I actually got it wrong, and then I got confused and then eventually got it right. They were asking me, "if you paid a pound..." and all these questions about the change. These were the kinds of questions they were asking me. I told them about my symptoms. I had the doctor's report, the neurologist's report, my rheumatology report. When I got home I got a letter say-

ing basically I got zero points altogether, that I had made my way there using map-reading, that there was nothing wrong with me and that I was fit to work’.

Samuel noted with dark irony that though he was declared fit to work by the authorities, it was essentially on health grounds that he had become unemployed in the first place. His desire to work has not been diminished, but he feels the stigma of the job centre: ‘they look on it like you don’t want to work. I do want to work, I want a normal life. I don’t want to be in the house the whole time, I want to go out and provide for my family’.

Samuel’s experiences are a harrowing example of the transformational nature of disease. His life has been, perhaps permanently, altered beyond recognition. Before he was attacked he worked two jobs and described himself as ‘constantly active, very fit’ with a ‘positive outlook on life’. In short, he has gone from being ‘a really happy person’ to one in the grips of despair, unsure of where to look for help and what steps to take towards recovery. ‘It’s got to the stage now’, he says, ‘where I’m unemployed, not entitled to anything...I don’t know where to turn. With the income coming into the household, I’m basically just above the breadline’.

Clearly, multiple anxieties converge upon a case such as Samuel’s: the frustrated ambitions of modestly providing for and raising a family and putting food on the table alongside a life now constricted and squeezed by medical realities, all the time in the shadow of mysterious and humiliating symptoms.

Samuel has found that singing in the choir his sister runs alleviates his problems, if only for a short time. When he sings, he feels the muscles in his back relax, and the pain leaves his body momentarily. Typical of the explanatory void in which fibromyalgia patients must live their lives, he is unsure of why or how this happens, but glad that it does.

Lauren’s experience is more ordinary than Samuel’s, but her life no less reconstituted by illness. Her introduction to the condition was more gradual, as she found

herself repeatedly getting ill without explanation or proper recovery. She contracted a serious chest infection lasted for four months and from there the symptoms worsened and spread, despite the use of steroids and antibiotics. Lauren began to hassle the doctors, telling them that she believed the pain was getting more severe: she was getting aches in her lower back and her right arm and shoulder seemed permanently sore. As she explains, it was hard work getting a referral:

‘It was a constant badgering, going to the doctors every week and saying I feel really ill. Nothing seemed to fit the pain. He’d done the blood tests and everything. Nothing came back, it was all clear. It took two years to get him to let me see somebody’.

In the end, she was sent to see a rheumatologist, who diagnosed her within ten minutes as having fibromyalgia, giving her a name if not a complete explanation for what she was going through.

Lauren’s experience here is fairly standard of the patients I interviewed, and it offers clues as to why some doctors dread dealing with fibromyalgia patients. She’s clearly in pain, but the pain is widespread, nonspecific and nonobservable. The GP thinks that they know what she is going to say before she comes in the door: that this hurts and that hurts and why can’t they do something about it? No doubt the medical professional feels somewhat helpless to aide such patients, who in turn feel frustrated that it seems as if the doctors are ignoring or downplaying their symptoms. Lauren recognises the difficulties faced by doctors, and shares in their frustrating ignorance: ‘they just don’t know what to do. They have no knowledge of fibromyalgia, and that’s the hardest part’.

Once she got a diagnosis and learnt a little more about the condition through personal research, Lauren thought back through her life and began to see a clear pat-

tern of tiredness, pain and infections. She now believes that these problems stemmed directly from sexual abuse she suffered as a child at the hands of her brothers and brother-in-law. We can see here what Hacking means when he talks about ‘making up people’: before her diagnosis, Lauren had been the victim of abuse as a child and then subsequently yet separately lived a life frequently interrupted by illness, which cumulated in her lengthy chest infection and the search for its explanation. Now, diagnosis in hand, she is able to make sense of her personal history in a new way, and events in her life that previously were explained away or forgotten clot around a new, all-encompassing explanation. This is not to say that in some way that her beliefs are correct, it is just to say that before she became aware of the category fibromyalgia, the inferences and connections she now draws between things that have happened to her had no soil in which to grow.

However, there were still times she doubted her label. Mostly this was due to the many-faced nature of what she was experiencing: how could all these symptoms belong to the same thing? ‘The pain was in my shoulders’, she said, ‘down my neck, down my back, everywhere. And I was incontinent. I thought, this can’t just be fibromyalgia. But that’s what I was told, that there are many elements to it. And that’s how it works’.

The pain became so much of an issue for Lauren that she had to give up work. She was always someone who worked, sometimes up to three jobs at the same time, and this change of lifestyle has been hard to swallow. Lauren talks of an utter transformation:

‘It’s just changed me completely. I’m stuck in the house. I go out twice a week for shopping and that’s it. I’m not the person I used to be at all. It has forced me into something, somebody that I’m not. And it’s very difficult when you’ve always been an active person. I feel like I’m missing out on life. People see me and think she looks well but they really don’t know what’s going on inside. I come home and cry

for no reason. I sit and cry and there's no reason whatsoever for it'.

Lauren's is not the only life left unrecognisable by her condition. Her husband, Gary, has become not just a partner but a full-time carer. He says 'I basically don't know who I'm going to get when I come home. There's no social life. And basically she's always...', his voice trails off before he says, 'she tends to require me all the time'.

Gary admits that he was sceptical for some time about his wife's health issues. 'It took me about twelve months', he says, 'to get over the idea that she was faking it. It was very difficult to understand the illness'. Now, though, he recognises in his wife a genuine dysfunction, and his concern is to care for her and to assist her in getting recognition and support from the state. He has been disappointed by what he views as the cynical attitude of those who determine whether or not she is eligible for social security payments:

'It took a long time to get disability allowance and even now we're getting home visits basically looking at ways of taking money off her. You only have to tell someone who comes to visit that you can walk so many feet and they'll take the money off you. Before this happened, I always thought it would be your worst case scenarios that they would take into account'.

I have drawn these three vignettes for the simple purpose of adding flesh and sinew to the dry bones of aetiology, diagnosis and pathogenesis, in order to show the ways in which theoretical conflicts and ambiguities play out in the lives of those in pain. Even from the short overview presented here of Lucy, Samuel and Lauren we can appreciate the complexity and frustration present in fibromyalgia, both on the part of the patient and on that of the doctor. We can also see clearly that the

arguments about diagnosis are not baseless, and that establishing a *positive* manner of diagnosing is nearly impossible at present. This is evident from the stories I have presented above: Samuel and Lauren are quite different in symptomatic presentation and the series of events that led to their problems are far removed, yet they still received the same diagnosis. It would seem fair to say that they have both received diagnoses of exclusion. Evident too is the swirling cloud of validation, legitimacy, stigma and epistemic injustice that seems to surround fibromyalgia patients: each of the three talked of being disbelieved, being suspected, being talked down to.

All of the examples presented above could be classified under Frank's scheme (discussed in Chapter I) as 'chaos' narratives, stories of individuals who have lost faith in the direction or substance of their condition, who begin to see no end to their symptoms. These individuals try to live day-by-day rather than indulge in thoughts of recovery, not because they would not like to recover but because they see little evidence to suggest that they will.

In the remainder of this chapter I will look at these issues and others in more detail, bringing into play the rest of my conversations with patients.

Pain and other symptoms

If there is one, central locus of fibromyalgia, it is pain. Underlying the headaches, interrupted sleep and forgotten words on the tips of tongues is the near-constant presence of bodily discomfort - aching muscles and searing joints. In this section I would like to examine this amorphous problem from a philosophical viewpoint. Generally speaking, pain is regarded as perhaps the archetypical example in discussions of solipsism, assessing the existence of internal states, scepticism about private language and the like.³⁷⁵ Indeed, the philosophical tradition of pain goes

³⁷⁵ Carel, H. 2016b, p. 123.

back millennia: what I would like to bring attention to in this section is the specific problems that pain in contested illnesses poses in contemporary settings.³⁷⁶

It strikes me that the questions we should ask of pain in relation to fibromyalgia are the following: how do patients describe and communicate their pain? - does this tell us what the pain is *like* or something else? - what is our reaction to the pain, as in, why the air of scepticism and the apparent downplaying of severity? - where do we think the pain comes from and why is this important? - and how do these questions relate to each other? The problem of pain as it relates to fibromyalgia is about belief and the conflict between medical and personal methods of communicating information about the body.

I doubt greatly that many fibromyalgia patients would take issue with René Leriche's description of pain as an object which is 'always purposeless'.³⁷⁷ Certainly, it is something they could do without.³⁷⁸ Two factors converge in the descriptions of pain that I heard from patients: its excruciating severity and its om-

³⁷⁶ I am not alone in thinking this is a pressing concern. Rita Charon said in 2016 that 'unremitting pain is...our contemporary central dilemma' as quoted in Padfield, D. and Zakrewska, J. M. 'Encountering Pain' in *The Lancet*, 2017, Vol. 389, pp. 1177-1178; on a side note, an interesting question for which we do not have the space to consider: in light of what has been discussed thus far in relation to identity and the socially-influenced mediation of experience, can we discuss pain as a historically consistent entity? In the same way in which I said on p. 134 that an identical act five hundred years apart (having sex with a man) is rendered fundamentally different by the social architecture which structures our interpretations, memory and indeed experiences of events, could it not be said that the pain Montaigne or Epictetus endured was somehow a distinct object from that which I feel when I stub my toe? Or have we not changed?

³⁷⁷ Leriche quoted in Buytendijk, F. J. J. *Pain*, 1971, Greenwood Press Inc., USA, p. 161.

³⁷⁸ Though perhaps not completely. Patients with a total inability to feel pain (congenital insensitivity to pain with anhidrosis) very often live difficult, truncated lives, and even regional insensitivity to pain can cause serious problems, as in peripheral diabetic neuropathy, where amputation after the fact is often not enough to save patients lives. See: Daneshjou, K., Jafareih, H. and Raeskarami, S. 'Congenital Insensitivity to Pain and Anhidrosis (CIPA); A Report of 4 Cases' in *The Iran Journal of Paediatrics*, 2012, Vol. 22, No. 3, pp. 412-416 and Pendsey, S. P. 'Understanding diabetic foot' in *The International Journal of Diabetes in Developing Countries*, 2010, Vol. 30, No. 2, pp. 75-79.

nipresence. Painkillers, lifestyle changes and meticulous planning all appeared to help individuals moderate the symptom but none would eliminate it entirely. Many spoke of the pain pulsing through their bodies twenty four hours a day, seven days a week, and the metaphors that some chose to use to illustrate their experiences speak of a group of people who firmly believe that what they are going through is without precedent in their pre-illness lives:

‘What’s the pain like? Gnawing. It’s constant. It’s always there. It’s kinda part of...I say it’s part of who I am now’.

‘What I can only describe as, it feels like, if someone put a candle under your skin. It feels like you’re almost on fire from inside. I know it’s weird describing it like that but that’s kind of what it feels like, that you’re actually burning from the inside out. It’s everywhere, it never goes’.

‘If someone said to me there was a pain like it I would have possibly told them it’s not true. Well you know what, there is pain like it. It’s horrible’.

In recounting their journeys from health to patienthood, it often seemed to me as if the pain began at a specific location, like in their lower back or down the side of one arm. However, as the search for a diagnosis wore on, the stories I was hearing from patients started to use more general terms. The pain had ceased to have a location and begun to spread, to the point where for many of the individuals I spoke with it was everywhere, in every system of the body.

This symptomatic profile has a limiting effect on people’s lives. That is to say, it reshapes what they are able to do on a day to day basis, but also on how they plan for their future. Chronic pain and its treatment seeps into many different aspects of

a person's life and changes the way they view possibilities. One patient, for example, spoke frankly about the fear that her symptoms might restrict her ability to raise children:

'I don't know if I could have children. I'm sure I could physically, as far as I know I'm fertile and stuff, but could I come off my medication for nine months? Because I can't take the stuff I'm taking while pregnant, it's dangerous. I'd have to come off that. And then lifting the child...if I do that it only makes it worse the next day and make the tiredness really bad. Because you need to physically look after a child...you can't just lie in bed all day if you've got kids'.

As I listened to patients talk about their symptoms and their consequences, I began to think often of the poverty of language in relation to pain and fibromyalgia. It is this deficit, this difficulty, which I will examine now.

Communicating pain

The trouble of conveying pain has, of course, famously been explored before, but it did not lead me in this instance to think about beetles in boxes. Or, at least, not straight away. I was first drawn towards the question of legitimacy in pain being a straightforward issue of inadequate communication.³⁷⁹ If patients could not translate their pain into accessible forms for others, would this go some way to explaining the lack of compassion they routinely received?

Certainly, a lot of the patients I spoke with suggested that unless you had the condition yourself, you would never truly understand what it felt like. 'Only people with the condition', said one patient, 'can understand how somebody feels'. 'People

³⁷⁹ Rather than a grander problem of language itself, *à la* Wittgenstein: see Wittgenstein, L. *Philosophical Investigations*, 2009, 4th ed., Wiley-Blackwell, UK.

don't understand what it's like', said another, 'they don't understand the amount of pain'.

There is a precedent here: fibromyalgia patients are not the only ones who have had issues communicating their symptoms. Many people with different conditions have likewise found the tools available to them inadequate for the task of getting others to understand how it is they are feeling.

Throughout the 1990s, Mark Collen suffered immense and chronic pain after herniating a disk in his lower back, causing long term nerve damage. He struggled to articulate how he was feeling to his practitioner and felt that the vision of true pain which he held both in his head and, against his will, in his back was obscured behind a clunky and inexpressive linguistic medium. In desperation, he turned to art as a method of conveying his symptoms visually. This form of representation actually improved the treatment he received as the doctors felt they better understood what was happening in Mark's body and how it was making him feel. Buoyed by this success, he founded *The Pain Exhibit* at the turn of the new millennium, an online collection of artworks produced by those in pain.³⁸⁰ It aims to educate health-care providers and the general public as to the unspoken and unspeakable nature of some illnesses, and though a fair number of them are harrowing, what is more striking is the directness with which they portray pain. These are not allusions to hidden disquiet, they are visceral demonstrations of agony, and they illustrate more than anything the penury of language when it comes to describing physical misery. Spurred on by this work and others, researchers since have tried to test the utility of using non-verbal communication tools in clinical settings, mostly through the employment of visual aides developed in conjunction with patients. The success of such approaches has been mixed, but what is of interest here is that their motivations emerge from the same problem: we struggle to talk about pain in a way that

³⁸⁰ <http://painexhibit.org/en/> archived on 19/07/17 at <http://www.webcitation.org/6s5GCCb2W>.

other people understand.³⁸¹

Virginia Woolf decried this exact issue nearly a century ago. ‘English’, she stated, ‘has all grown one way’: towards romance and psychology and schemes, greed and jealousy, power and attraction.³⁸² Little attention is given to the body, which ‘all day, all night...intervenes’. Indeed, ‘the merest school girl, when she falls in love, has Shakespeare, Donne, Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry’. It would appear that we have not expanded our means of expression sufficiently in the years since.³⁸³

For writers like Scarry, it is not illness in general but pain specifically where our language is unable to bear the load placed upon it.³⁸⁴ There is a fissure between the irrepressible veracity of being in pain and the detached uncertainty of viewing others in apparently similar situations. As she writes: ‘to have pain is to have certainty; to hear about pain is to have doubt’.³⁸⁵

Part of this doubt comes down to the bluntness or inappropriateness of the tools

³⁸¹ For example: Main, S. ‘Picturing pain: using creative methods to communicate the experience of chronic pain’ in *Pain News*, 2014, Vol 12, No. 1, pp. 32-35; Padfield, D., Zakrzewska, J. M. and Williams, A. C. C. ‘Do photographic images of pain improve communication during pain consultations?’ in *Pain Research and Management*, 2015, Vol. 20, No. 3, pp. 123-128.

³⁸² Woolf, V. *On Being Ill*, 2002, Paris Press, USA.

³⁸³ It is not just a problem of the English language, either. Canguilhem writes (in French): ‘It is impossible for the physician, starting from the accounts of sick men, to understand the experience lived by the sick man, for what sick men express in ordinary concepts is not directly their experience but their interpretation of an experience for which they have been deprived of adequate concepts’, in Canguilhem, G. *The Normal and the Pathological*, 1991, Zone Books, USA, p. 115.

³⁸⁴ Scarry, E. *The Body in Pain: The Making and Unmaking of the World*, 1985, Oxford University Press, USA; see also Neilson, S. ‘Pain as metaphor: metaphor and medicine’ in *Medical Humanities*, 2015, Vol. 1-8, doi: 10.1136/medhum-2015-010672.

³⁸⁵ Scarry, E. 1985, p. 13.

we employ. Scarry takes particular issue with the metaphors commonly used by those in pain, and splits them into two types: patients, she says, talk of either an ‘external agent’ or of ‘bodily damage’. The former frames pain in imagery of attack from or damage sustained as a result of something coming from outside: a hammer, a drill, a knife, a flame. The latter discusses pain in terms of broken bones, twisted muscles, aching organs. Neither of these approaches, argues Scarry, provide the listener with an ‘identical’ description of pain. They are rather referents or associative images that approximate a nonreferential process. That is to say, their use separates our vision and understanding of the pain from the pain itself: we visualise the hammer or the broken bone rather than placing the pain in its actual context, no matter how nebulous it might appear to us.

This being true, it is still possible to impart a portion of our physical experience to others through imagery; we are not entirely impoverished linguistically, and I am in no doubt that the more articulate among us can paint vivid pictures of their interior landscapes. Certainly I can think of many memorable descriptions of pain in fiction, such as the following by Updike (who so often wrote beautifully on pain) in his novel *The Centaur*:

‘By searching through his body he can uncover any colour and shape of pain he wants: the saccharine needle of the toothache, the dull comfortable pinch of his truss, the restless poison shredding in his bowels, the remote irritation of a turned toenail gnawing the toe squeezed beside it in the shoe, the little throb above his nose from having used his eyes too hard in the last hour, and the associated but different ache along the top of his skull, like the soreness left by his old leather football helmet after a battering scrimmage down in the Lake Stadium’.

Or Lorrie Moore’s wonderfully succinct and evocative portrait of a headache:

‘...sometimes the zigzag of a migraine made its way into her skull and sat like a cheap, crazy tie in her eye’.

Even if we admit that pain is ultimately incommunicable, it is not clear why using metaphors and imagery such as in the passages above that allow us at least an indication of what another person is going through is worse than giving up on the idea of communication at all. In a clinical setting, throwing your hands up and stating that pain speaks in an inaccessible language and therefore not worthy of effort is a non-starter.

In fact, most of the patients I spoke with had little problem putting their problems into words, and many refrained from using metaphors at all: they talked about pain as something self-evident and were more interested in communicating its reach - both across their bodies and across their lives. What I am trying to say by all this, however circuitously, is that it is not the inherent deficiency of language that leads to miscommunication or scepticism in relation to fibromyalgia patients’ pain. Their ability to describe what they are going through in words is just as adequate as a non-specialist with cancer, and so the suspicion - and I think suspicion is the right word here - must come from somewhere else.

Non-verbal communication

An important and obvious point to raise at this stage is the fact that pain is communicated by more than just language. The state of being in pain is expressed to and understood by others not just, or even most often, through words but by means of ‘serialised bits of pain behaviour – grimacing lips, wincing eyes, moans issuing from the larynx, writhing torsos, and so on’.³⁸⁶ It is because of this visual,

³⁸⁶ Schrag, C. O. ‘Being in Pain’ in Kestenbaum, V. (ed.) *The Humanity of the Ill*, University of Tennessee Press, USA, 1982, p. 117.

physical performance of pain that we nonetheless understand when children or animals who cannot tell us how they feel are hurt in some way. Fibromyalgia patients talked about crying with pain, about rolling into balls and about being unable to stand for a few minutes because of the intensity of feeling, but they also told me about covering up their symptoms, wearing a mask in front of others and finding ways of dealing with what their body was telling them without showing it. I wondered whether then the problem was not of communication per se, but the precise method and manner in which these patients were trying to express themselves. For most people extreme pain has an immediacy to it - a broken leg cannot be ignored for too long, individuals stung by a box jellyfish cannot hold long discussions, etc. - but the patients I spoke to were able to hold cogent and involved conversations with me, some lasting upwards of an hour, in spite of what they described as debilitating, extraordinary discomfort. I do not wish to be misunderstood on this point: I am not casting doubt on their testimony, but rather questioning to what extent our acceptance of another's pain lies in the way in which it is conveyed. For the worst pain, people around the patient seem to need more evidence than to be simply told *it is the worst*. They need to see that it is the worst, and to understand how it came about. Our powers of empathy do not exist in an explanatory void. But I am getting ahead of myself.

This is a problem which has been identified before in relation to psychosomatic illnesses. It was noted that despite being paralysed or bedridden or suffering some other unfortunate fate, patients often seemed unperturbed by their situation, almost cheerful to be wheelchair-bound or paralysed. This surprisingly care-free reaction was regarded as a strong indicator that the symptoms had no identifiable biological base, and was known as 'la belle indifference', or, literally, 'the beautiful

indifference'.³⁸⁷ The patients I spoke with were not care-free, and neither did they downplay their symptoms, but I cannot help but be reminded of my experiences speaking with some young doctors in Australia.

We were sitting in a pub garden under the Melbourne sun and talk had turned to my research. I was keen to hear what their experience with fibromyalgia had been, given that they worked in various parts of a hospital rather than a surgery and so occasionally saw patients with fibromyalgia brought in from A&E. One of them told me that the typical fibromyalgia patient they'd see would be a woman who appeared normal and might be playing on their phone or reading. Upon admission they would inform the medical staff that they were in excruciating pain, that everything hurt and that they were ten on the pain scale. Throughout, the patient would seem fairly calm and unperturbed. Finally, they would ask for painkillers.

Some of the other doctors nodded in agreement at this portrayal.

No doubt this is a caricature, perhaps exaggerated by the presence of a crowd and a few Victoria Bitters, and a portrait which fibromyalgia patients themselves would wince at (doctors too perhaps), but it illustrates my point: it is not enough to *say* you are in pain in order for that pain to be recognised. This doctor's scepticism, in large part, was founded upon the discrepancy between the pain being reported by the patient and the corresponding enactment of that pain; he simply did not believe that someone who rated themselves that highly on the pain scale would be able to maintain a conversation, entertain themselves on a phone and generally continue to function. To put this in perspective, to report yourself as suffering from that level of pain is to put yourself in a category of distress 'so intense you feel you

³⁸⁷ As a clinical sign it has been deemed too ambiguous to be of use in contemporary medicine: Stone, J., Smyth, R., Carson, A., Warlow, C. and Sharpe, M. 'La belle indifférence in conversion symptoms and hysteria' in *British Journal of Psychiatry*, 2006, Vol. 188, pp. 204-209.

will go unconscious shortly'.³⁸⁸

There may be a biological component to this. Much neurological research has been conducted over the last decade or so which demonstrates that the human brain reacts differently depending on whether it is empathising with another person in an embodied sense, that is to say an individual vicariously shares the emotional sensations of another, or whether the interaction is based upon 'cognitive perspective taking', or a process of reasoning about the intentions, thoughts, feelings and beliefs of another person.³⁸⁹

Interestingly, when *empathising* with a person in pain, many of the same parts of the brain show activity as when we are in pain ourselves.³⁹⁰ This is why it is difficult, especially in person, to witness the distress of another individual or even an animal. Often we find ourselves involuntarily turning away or feeling uncomfortable, not to mention the rising urge to help or allay their pain if we can. However, when reasoning about a person in pain, taking their cognitive perspective as it were, different areas of the brain light up.

What this suggests is that there is a biological element to empathy, and that this is activated visually and automatically. Could it be possible, then, that in the case of fibromyalgia patients, the disconcerting (from the perspective of the viewer) lack of

³⁸⁸ Based on this pain scale: https://lane.stanford.edu/portals/cvicu/HCP_Neuro_Tab_4/0-10_Pain_Scale.pdf archived on 19/07/17 at <http://www.webcitation.org/6s5GItL7Y>; others are comparable.

³⁸⁹ Hein, G. and Singer, T. 'I feel how you feel but not always: the empathic brain and its modulation' in *Current Opinion in Neurobiology*, 2008, Vol. 18, pp. 153-158.

³⁹⁰ Betti, V. and Aglioti, S. M. 'Dynamic construction of the neural networks underpinning empathy for pain' in *Neuroscience and Biobehavioral Reviews*, 2016, Vol. 63, pp. 191-206.

visible anguish works against them in terms of gaining sympathy?³⁹¹ - and that this lack of sympathy, or diminished empathy, detracts from the legitimacy of their pain subconsciously? Fibromyalgia patients that I spoke to complained frequently that others did not see them on bad days, as during flare ups or other bad periods they did not leave the house, go to work or attend doctor's appointments. More ordinarily, they try to hide what they are going through in order to make their lives easier. As one patient put it:

'You learn to wear a mask. When people are crossing the street and they say "oh good morning, how are you?"', the answer is "fine thank you, how are you?" and everyone goes their own way. Nobody actually wants to know the answer to their question. It's a nicety'.

Another sufferer had come to the conclusion that fibromyalgia is too complicated and confusing to explain every time they met someone new:

'I've given up trying to tell people what I have, I just say I'm fine. It's difficult to explain how it's had such an immense effect on my life and I don't think anybody could understand that'.

Is it possible that all these problems of communication stem from the same place, I wonder? Is it that the pain felt by fibromyalgia patients is somehow different from

³⁹¹ It has long been noted in disability studies that lay reactions to different disabilities rely upon contextual and visual knowledge (i.e. how much the dysfunction 'stands out', the meanings surrounding it and how it is encountered). For examples, see Wright, B., 'Attitudes and the fundamental negative bias: Conditions and corrections' in Yuker, H. (ed.), *Attitudes toward persons with disabilities*, 1988, Springer, USA, pp. 2-21; Schmelkin, L. 'Multi-dimensional perspectives in the perception of disabilities' in Yuker, H. (ed.) *Attitudes toward persons with disabilities*, 1988, Springer, USA, pp. 127-137.

‘ordinary’ pain and therefore necessarily divergent too in its interior presentation? Would this not make it both harder to express and less easy to recognise? Are there different types of pain?

Different types of pain

People without medical or scientific backgrounds tend to have a singular notion of pain: that it has many adjectives but belongs to just one category. Pain can be gnawing, biting, aching, shooting etc. but there is no Pain A and Pain B. Physiologically, this is incorrect. Pain experts have for some time distinguished between nociceptive and neuropathic pain. The former is pain as a nervous response to injury, a message sent through the body as a result of injury or inflammation; the latter emerges as part of damage to the nervous system itself.³⁹² Where nociceptive pain is usually time limited and easily alleviated, its neuropathic brother is less easily contained, often persisting over many years and proving resistant to treatment. Fibromyalgia patients do not show any measurable signs of these types of pain and as stated above, there are a distinct lack of biomarkers in relation to their condition. And yet the patients are so clearly in pain. Davis and Vanderah have recently argued that the reason for this is because fibromyalgia patients do not suffer from either of the two types of pain detailed above.³⁹³ Rather, they posit that traumatic experiences, especially those that occur when we are young, can rewrite our nervous systems and make us susceptible to exaggerated pain responses in later life without corresponding tissue damage. Furthermore, they hypothesise that clinical

³⁹² Examples of nociceptive pain: broken bones, sprains, burns, obstructions. Examples of neuropathic pain: post herpetic neuralgia, phantom limb pain, carpal tunnel syndrome, reflex sympathetic dystrophy.

³⁹³ Davis, B. and Vanderah, T. W. ‘A new paradigm for pain’ in *The Journal of Family Practice*, 2016, Vol. 65, No. 9, pp. 598-605; Davis is a doctor who specialises in pain medicine, Vanderah a neurologist.

attitudes towards pain which view it as strictly nociceptive or neuropathic, actively harm the doctor patient relationship in instances such as fibromyalgia. I would extend this point to more general reactions to pain: pain without tissue damage, organ dysfunction, inflammation or bruising is harder to understand and harder to believe.

It is also harder to treat. A varied back-bar of opioids, anti-depressants, anti-inflammatories, muscle relaxants and sleep medicines are prescribed to patients, normally on a tailored, trial-and-error basis. Of the three drugs that are FDA approved, pregabalin (marketed as Lyrica), duloxetine (sold as Cymbalta) and milnacipran (Ixel, Savella, Dalcipran, Toledomin), two are SNRIs also used to treat depression and similar disorders and one is an anti-epileptic drug.³⁹⁴ None of the three has been found to treat patients with great consistency or efficacy, and many patients regularly take large doses of each without witnessing a corresponding drop in symptom severity.³⁹⁵

How this relates to the notion of pain, or of differentiating within pain, is down to the fact that individuals now have an expectation that medicine will be able to reduce suffering in almost all cases. As one patient said:

‘My dad died of a cancerous tumour and my aunt died of bowel cancer and I remember being told that they would never have to be in pain. Nobody had to be in pain. So why is it I have to live in constant pain and nothing can stop that pain? I find that hard to get my head round’.

³⁹⁴ SNRI stands for ‘serotonin-norepinephrine reuptake inhibitors’. They are a class of antidepressant drugs commonly used to treat depression and similar conditions.

³⁹⁵ They appear to work on a limited and piecemeal basis, proving marginally effective for a minority of patients: Theoharides, T. C., Tsilioni, I., Arbetman, L. *et al* 2015, pp. 255-263.

The fact that painkillers that work so well for other instances of pain fail to have a similar effect on the symptoms of fibromyalgia patients serves to increase the feeling of isolation and alienation on their behalf in regard to their bodies, the simple question being that if this were *normal* pain, then surely it would be subject to the same physiological laws and treatable by the same drugs?

To collect the pieces thrown out so far in this section and begin to assemble them, it seems we can say the following. Fibromyalgia patients have problems in the linguistic communication of their pain, but these problems are not any more severe than some other conditions. It may be that physical presentation is an issue, that fibromyalgia patients don't look like they are ill, or like they are in as much pain as they say they are. This is compounded by what could be called their invisibility, the fact that many of them do not seek company or leave the house on their 'bad' days, and by the biological evidence that visual cues are necessary for deep empathy. Furthermore, this might be in part elucidated by the *strangeness* of the pain felt, suggesting a wholly different bodily process. However, there is a further avenue to be explored, that of explanation. The pain that fibromyalgia patients feel exists in an explanatory vacuum. I believe it to be true that, however rudimentary and unscientific, other people require some coherent account of the pain in order to recognise it as legitimate.

I use the word 'recognise' here quite deliberately. When we see someone we know in a crowded place, we do not necessarily think of where we know them from, but we are certain that we have met or seen them before. This is how it often feels in relation to contested illnesses, but inverted: they are in a familiar crowd but we do not recognise them, we have not seen them before, they do not fit the category of faces that we have crossed paths with previously. Encountering the pain of a fibromyalgia patient is like meeting someone you think you might know from somewhere but don't; you ask them if they went to this school or used to drink in that pub, and when the answers come back negative you conclude that in fact you do

not know this person. We ask: is it something to do with your muscles then? - did they find a problem with your spine? - do you need an operation? and when the answers come back we find ourselves looking at something unknown and therefore fill in the explanatory void with other inferences.

The sort of reasoning that fills this gap will be explored in greater detail later on in this chapter as it intersects with ideas about work and welfare but it is worth considering quickly. Given the difference between automatic empathy and cognitive perspective taking, is it not reasonable for individuals considering the fibromyalgia patient, on the basis of their presentation, to downplay their symptoms for good reasons?³⁹⁶ In that, having put themselves ‘in the shoes’ of a fibromyalgia patient, they have concluded that on the balance of evidence that it is more likely that patients are not in fact feeling pain at all? Certainly some individuals do feel like this, and patients spoke frequently about coming up against the attitude that what they were relaying about their subjective state was subservient to the lack of ‘objective’ markers of debilitation.

Although this section is beginning to get conceptually crowded I would like to raise another point, or rather ask another question: is it possible that some of us believe that fibromyalgia patients *are* in pain, but we disbelieve the pain itself? To put this another way, is it that we understand and appreciate that a fibromyalgia patient feels pain, but the lack of physiological basis for that pain leads us to think that either that pain is not worthy of the same sympathy as other instances of discomfort or that somehow that pain is ‘not real’?

This is a moral standpoint that, if not necessarily explicitly and consciously taken, is definitely *felt* to be taken by many in the eyes of fibromyalgia patients. The dreaded sentence ‘it’s all in your head’ was repeated frequently by the individuals I spoke with: the implication being of course that though they may well be feeling pain, that pain was self-generated, an internal creation rather than an external

³⁹⁶ See p. 167

threat and, most of all, controllable.³⁹⁷ In other words, because of the lack of an explanatory framework, their pain was not as worthy as other forms of pain:

‘My neurosurgeon, who did my spinal surgeries, when I was still having so much pain after the last surgery, he was basically telling me it was all in my head and that the x-ray and MRI look like they should and so I’m basically just imagining it and remembering the pain I was in’.

‘Some of them don’t believe that it actually exists. One of the consultants, he told me it was all in my head. It’s very, very difficult. It feels like you’re trying to convince them you’re ill’.

Pain here takes on the quality of being genuine in these scenarios then not because it is felt, but because of its origins. Legitimacy is given not in the case of pain being reported, but in the context of how that pain came about and in what ways we can view it. Of course, different people have different reactions to the pain of a fibromyalgia patient, and I am only analysing here a few responses. But there are patterns, certainly, and, however impressionistically, I have touched upon a few above.

There is one further point I would like to make about pain. In Wittgenstein’s much repeated and discussed private language argument, he uses pain as a prime exam-

³⁹⁷ Incidentally, this phrase was used as the title of Suzanne O’Sullivan’s Wellcome Book Prize winning work, bizarrely later published as ‘*Is it all in your head?*’ (my emphasis). The subtitle - ‘True stories of imaginary illness’ - remained the same between editions. The pronounced difference between these two titles does not obscure the central point: diseases can be ‘all in your head’, your head in this case being a metaphorical repository for unhappiness and, subsequently, a subconscious puppeteer of your body. See: O’Sullivan, S. *It’s All in Your Head: True Stories of Imaginary Illness*, 2015, Chatto and Windus, UK.

ple.³⁹⁸ He states that there is little difference between saying ‘I know I am in pain’ and saying ‘I am in pain’, because it is incoherent to talk about knowledge of interior sensations in the same way they we deal with exterior facts (i.e. investigation, verification, justification, truth etc.). As Schrag puts it, ‘knowing that one has a pain in his foot is assuredly quite different from knowing that a fifth of Beefeaters gin is in the liquor cabinet’.³⁹⁹

However, I do not believe it to be an outrageous stretch of the imagination to consider the idea that for fibromyalgia patients, the statements ‘I know I am in pain’ and ‘I am in pain’ are not straightforwardly identical, and in fact might not be held to be true simultaneously or at least clash in some previously unforeseen way.

Wittgenstein does not think that we can talk about pain in terms of knowing because it is an internal, subjective phenomenon that we simply *feel*: we are either in pain or we are not, and we cannot submit it to the same analysis that we can other pieces of knowledge about the world. This argument is, of course, grammatical rather than metaphysical: it is about how we use language. I do not intend to challenge this view.

Instead, I intend merely to use his arguments about ‘knowing’ pain as a way of illustrating the doubt felt by patients, who themselves are not outside of the explanatory void viewpoint I suggested above might account for a portion of the scepticism afforded to their symptoms. Certainly, the indication that several patients gave me was that the lack of positive biomarkers, the inability of others to recognise their pain, the attitudes they came up against, led them in some way to doubt that they were feeling pain at all. This is because they treated ‘pain’ as an object of knowledge in precisely the way which Wittgenstein said it would be nonsensical to do so, as something to be weighed against the evidence, a framework in which subjective feelings could be overruled, as if it were an external artefact rather than

³⁹⁸ Wittgenstein, L. 2009, pp. 95-111.

³⁹⁹ Schrag, C. O. 1982, p. 111.

something intangibly personal and interior:

‘I doubted myself, that’s exactly what happened. They had me thinking is it really in my head? Have I really got it? I was doubting myself at one point because no-one was listening to me and I was thinking oh surely, they’re professionals, they know what they’re doing’.

‘I’ve been to the doctor and said “am I making this up? Why aren’t these painkillers working? Is this just all in my head?”’.

This doubt leads a patient to think that what they have *isn’t pain*, and thus they might say ‘I am in pain’ because our language does not provide them with an alternative and appropriate way of expressing their interior sensations - i.e. something that resembles pain enough to be considered but fails to meet some external criteria - whilst simultaneously and, sincerely, stating that ‘I know I am not in pain’. Goldberg makes a similar point to this, though he argues that what is occurring is not the simultaneous in pain/not in pain dichotomy that I have drawn above but rather a question of denying the legitimacy of real, irrepressible sensations:

‘By visually representing the pathologies inside the human body, the truth of the phenomenon in question can be discerned. But note that it is not merely the physician qua investigator who uses images of the anatomised body to verify the truth of the matter. The pain sufferer himself/herself/themselves also draw on the epistemic power of the correlative pathological object inside the human body. While pain sufferers do not have the luxury of denying the reality of their pain, they can and do deny its legitimacy, thereby internalising the stigma so frequently directed

at people in pain'.⁴⁰⁰

This discussion rests heavily on the thought that pain has become an object which is visible in a shared sense, and that which cannot be seen or leaves no physiological trace must be something else, something not-pain. We are getting close to the point of saying here that science has allowed us to look at each other's beetles, and that is partly what I am saying. An analogy would be to say that though we all continue carry around boxes with a thing we call a 'beetle' in it, we also do so in a society with rudimentary x-ray technology (technology that also carries a lot of prestige) which allows us to view blurry scans of other people's beetles. Most correlate roughly with each other, but some seem incongruous, despite their owner's insistence that what is in their box is a beetle like all others. It is these people we begin to distrust, suspecting that they are not in possession of a beetle as we understand it, despite having limited knowledge ourselves. This view roughly correlates to the situation fibromyalgia patients find themselves in, where modern medical apparatus allows us to view the footprints of pain but theirs leaves little trace.

Pain is not the only symptom of fibromyalgia, however. Patients also report cognitive problems with speech and memory, which we will turn to now.

Dyscognition

⁴⁰⁰ Goldberg, D. S., 'Pain, objectivity and history: understanding pain stigma' in *Medical Humanities*, 2017, Vol. 0, pp. 1-6, doi: 10.1136/medhum2016-011133; this statement is supported by research he draws upon by Rhodes: Rhodes, L. A., McPhillips-Tangum C. A., Markham, C. *et al* 'The power of the visible: the meaning of diagnostic tests in chronic back pain' in *Social Science and Medicine*, 1998, Vol. 48, pp. 1189-1203.

One of the strangest symptoms of fibromyalgia has been termed fibro fog:⁴⁰¹

‘What I’d call ‘fogginess’, lack of clarity of thought. I’ll go to do something and forget what I was going to do in the first place and end up doing something completely different. For example, I thought I’d emailed you but I hadn’t. It’s frustrating’.

‘Sometimes when I’m cooking, something is in a different pan or in the top oven and I forget about it so it just gets left, or it burns, or we just don’t eat it because I forget. So we have two thirds of the meal rather than the whole meal...we had a house fire a couple of years ago because I left something on the cooker and went out’.

‘My memory is horrendous. I sometimes can’t remember something that happened thirty seconds ago. I can’t remember the names of people that I’ve known for twenty years. I look at them and think, I know you, but I can’t come up with their name’.

This may well read like the ordinary consequences of ageing and perhaps, given a certain angle, evidence of the confirmation bias present in a condition like fibromyalgia. Those of the social construction/medicalisation/iatrogenic school of thought would certainly be tempted to argue that the above is evidence of what they already know: people with fibromyalgia become ultra-sensitive to what are simply the normal biological effects of time passing. Healthy people forget things,

⁴⁰¹ For a clinical overview, see: Kravitz, H. M. and Katz, R. S. ‘Fibrofog and fibromyalgia: a narrative review and implications’ in *Rheumatology International*, 2015, Vol. 35, pp. 1115-1125; Ambrose, K. R., Gracely, R. H. and Glass, J. M. ‘Fibromyalgia dyscognition: concepts and issues’ in *Reumatismo*, 2012, Vol. 64, No. 4, pp. 206-215.

just like healthy people feel tired and healthy people ache. The hypersensitivity to symptoms which lie on a normal spectrum of distress is precisely what is causing the problem in this view: and a tendency to search symptoms online rather than engage with traditional constraints against illness behaviour (such as close family members) serves to exaggerate the meaning of these symptoms further until they metastasise into a full blown 'illness career'.⁴⁰² Barsky and Borus, in line with this perspective, argue that 'the suffering of these patients is exacerbated by a self-perpetuating, self-validating cycle in which common, endemic, somatic symptoms are incorrectly attributed to serious abnormality, reinforcing the patient's belief that he or she has a serious disease'.⁴⁰³

In thinking about this view I am reminded of the episode of *Hancock's Half Hour* where Tony Hancock appears in a state of histrionic convalescence, sitting at his kitchen table inhaling Vicks vapour whilst surrounded by a variety of bottled remedies. Appealing for compassion from his friend Sidney, his concerns are given short shrift:

Sidney: 'What's the matter, you've got a cold? You want sympathy? Everybody gets colds'.

Tony: 'Not like I get them'.

Sidney: 'Of course they do'.

⁴⁰² See the section on Shorter in Chapter III.

⁴⁰³ Barsky, A. J. and Borus, J. F. 'Functional Somatic Syndromes' in *Annals of Internal Medicine*, 1999, Vol. 130, p. 910.

Tony: 'No they don't. Samples, that's all they get. Me, I get the full output of the entire germ kingdom'.

Besides being perhaps the first recorded instance of 'man-flu', this exchange is illustrative of the attitudes that fibromyalgia patients sometimes face: that there is nothing especially unique about their symptoms and that what they were feeling was the 'ordinary' aches and pains of life. The implication here is that they, like Tony Hancock, are not truly or at least seriously ill but merely being melodramatic. As one patient told me:

'It's very difficult because if somebody asks what's wrong with you, to try and explain what fibromyalgia is you'll be there forever and people don't want to be lectured. So if you say to somebody "I've got chronic fatigue" their usual reaction is well I get very tired as well and it's frustrating because you need to explain to them that chronic fatigue is not the same as just being tired. Sitting down and having a cup of tea will not fix it'.

Fibromyalgia does not only affect the elderly, but also can be found in young and middle aged individuals who we would not expect to have pain or memory symptoms *at all*. The fact that these patients feel they have the same complaints as older sufferers casts doubt on the idea that fibromyalgia is simply hypervigilance to the creaky facts of ageing. For example, a woman in her early twenties told me about her cognitive problems, not ordinarily associated with people her age:

'I get fibro fog, that is awful. It's almost the worst part. You literally become unintelligent, you can't focus on anything long enough to do anything and you just can't get your brain going'.

These issues - fibro fog or 'dyscognition' - have attracted increased clinical attention recently, but that is not what I would like to focus on. Instead, I'd like to make the point that cognitive problems, alongside the gamut of other symptoms fibromyalgia patients experience, alienate patients from other people's expectations of a diseased body. Using the terminology I introduced above, fibro fog and other symptoms, of which there are an incredible multitude, make fibromyalgia patients harder to 'recognise'.

The reason for this again comes down to expectations. When we encounter illness, we (the lay population) expect it to manifest consistently (to our expectations of consistency as it relates to disease). If you have X, we reason from experience, then that means you will get symptoms Y and Z. One fibromyalgia patient, on the other hand, might present with symptoms Y, G and B, whereas a different patient shows symptoms Z, D and K. The relationship between the symptoms themselves are important too: through the lay knowledge of medicine we pick up over the years, certain complaints cluster together. A pain in the gut and constipation for instance, or yellow eyes and jaundice, or fever and a runny nose. Less common combinations involving, say, muscle pain, forgetfulness and fluctuating numbness in your right hand, are harder for people to place, harder to recognise, and without a cogent explanation (which with fibromyalgia is rarely forthcoming), harder to believe. This is made all the more difficult when you consider that another fibromyalgia patient might experience different symptoms - what is an observer to make of all this?

Think back to my examples at the beginning of this chapter. A large portion of Samuel's complaints regarded seizures, something that none of the other patients I interviewed reported. One patient described violent shaking, another talked about problems with sweating. A female patient I spoke to even said that pain was not her main complaint. This inconsistency of presentation goes directly against what we

would normally expect to see in a disease.⁴⁰⁴

I seem to be making the case, as others have, that fibromyalgia is a hopelessly vague diagnosis, accommodating a large number of individuals with different complaints. But this reasoning itself speaks to our implicit idea of disease. That is to say, as obvious as it is to point out, our entire causal conception of illness is one which privileges consistent outcomes, regardless of whether the explanatory weight is put on mechanistic or probabilistic footing in any particular instance. This makes sense, but it is not a model that fits fibromyalgia patients - or, to strip away their label, *this symptomatic population*. Because here's the crux: take away their diagnosis and these patients would still feel ill, would still appear in doctors' clinics, would still have trouble functioning on a day-to-day basis.⁴⁰⁵ They *do* have many of the same problems, in a broad sense, and what matters here is that they are treated by others on the basis of possessing *something unitary*, irrelevant of how fluid that thing is.

There is a final layer of inconsistency to be addressed. Frank, as discussed at vari-

⁴⁰⁴ I am not saying that all diseases are symptomatically consistent: this is patently false. I am talking in terms of expectations - the subtle, subterranean rudders that guide our gaze. In 'recognised' conditions with variant symptoms there are two factors which explain our 'lack of surprise', or in other words two factors that account for divergent complaints not serving to delegitimise a condition. Firstly, though different symptoms may appear in different individuals, these patterns are normally mapped and so a symptom, though not necessary, will be regarded as sufficient for that condition and not unusual. That is to say, though patients may experience any one of a number of complaints, these symptoms will not display the same chaotic randomness that they appear to in fibromyalgia patients. Secondly, an explanatory framework will normally exist which can provide causal links between symptoms and disease in a way that is not possible, or not currently possible, with fibromyalgia.

⁴⁰⁵ There are no doubt many people who would disagree with this point (some of whom were discussed earlier in this chapter) and contend that if you took away the diagnosis then there would be no disease and patients would be more likely to recover. The basis on which I dismiss this iatrogenic model is simple: talk to patients and more often than not you will find that symptoms persisted for years before a diagnosis was arrived at. And even the possession of a diagnosis such as fibromyalgia is, I believe, an underdetermined factor in the generation and maintenance of symptoms as many sufferers recognise its vagueness and imprecision. It is a loose net, for sure, but the fish it trawls were already in the water.

ous points above, details the ways in which sick people think about their illnesses narratively.⁴⁰⁶ He states that generally speaking we in the West are preoccupied with restitution narratives, those which tell of healthy people struck down by disease but on the road to recovery - a road which is linear and straightforward. Less thought is given, he says, to chaos narratives: stories of illness with no endpoint and little internal consistency. There is no happy ending with a chaos illness narrative because more often than not there is no ending at all.

Quotes like the following illuminate the trouble that patients have making narrative sense of their disease and its symptoms:

‘They say “we’ll just up your morphine, that’ll get rid of some of your pain” and it will but it just goes round and round. I just think why can’t you treat the cause. They don’t seem to know anything about the cause. I feel like they can’t do anything apart from up my medication and I don’t want to have it up because then it makes me more tired and sleepy. Is this my life? I’m going to constantly climb up on this painkiller regime until...until what? They can’t give me any more? And then I just live in pain or...I don’t understand it. I’m not sure where it’s going’.

This sense of unstructured, open-endedness speaks to the experience of fibromyalgia patients and though many individuals find ways of living with their symptoms and redesigning their lives in a way that allows them to function better, the restitution of the body to previous levels of health is rare. But more than this aspect of their condition is chaotic: their symptoms, varied as they are in form as detailed

⁴⁰⁶ Frank, A. 2013; the illness narrative literature that Frank contributes to is rich and varied, see Kleinman, Charmaz and Charon for seminal texts: Kleinman, A. *The Illness Narratives: Suffering, Health and the Human Condition*, 1988, Basic Books, USA; Charmaz, K 1993; Charon, R. *Narrative Medicine: Honouring the Stories of Illness*, 2008, Oxford University Press, UK; see Bury for a good overview of the literature: Bury, M. ‘Illness narratives: fact or fiction?’ in *Sociology of Health and Illness*, 2001, Vol. 23, No. 3, pp. 263-285.

above, vary also in severity. This is bewildering for patients; for those around them it jars with what they believe disease to be. We believe that symptoms do not simply flit about the body like a child walking at random between rooms of a house, and neither do they appear, disappear and then reappear without any apparent (or, at least, proportional) corresponding *reason*.⁴⁰⁷ So when we see a person who, one day to the next, appears to oscillate between physical destitution and well-enough seeming periods of energy and health, we find it difficult to assimilate this information into the biomedical matrix that informs our understanding of disease. It doesn't fit.

Some of the patients I spoke to recognised that this was a factor in their condition not seeming valid:

'It changes so much, one minute I'm lying dead on the couch the next minute I'm like let's go cook dinner. I think that's got to be hard for them [her family] to deal with'.

This issue - the inconsistency of symptoms - and the way it is handled by doctors, patients and the people around them, will emerge in different forms as we go through this chapter. Along with the other items discussed above with regard to pain, explanation and belief, it can be a key reason why fibromyalgia patients feel delegitimised, their symptoms not as valid as other ill people's. In the next section, I will look at what relationships can tell us about our collective conception of disease and make the case that for many patients the interactions they have with their family, friends and colleagues in relation to their condition are more important in determining their wellbeing than the medical care they receive, something which

⁴⁰⁷ For instance, one patient told me: 'some days it might just be one bit, or start in one bit and go round the rest of the body, or I've had days where it's been full on, everywhere, stabbing pains all over'.

has been neglected in previous philosophical treatments of disease, which tend to be more focused on concepts as they relate to healthcare and science.⁴⁰⁸

Relationships

A large portion of the philosophy of medicine literature focuses on how we should define certain concepts - health and disease being the main players. Implicit (and occasionally explicit) in these discussions is the salience of deferring to medical definitions and usages of terms. On the one hand this is intuitive: most of what we know about disease, biologically, comes from medical science and discussing illness without talking about healthcare or 'medicine' seems deficient. But on the other hand, as I discovered throughout my conversations with patients, though medical definitions are extremely important and interactions with healthcare providers laced with meaning, doctors are not the only ones who define disease, and whose definitions have an impact on patients.

I am not here talking about the web of interests that often encircles a disease - the pharmaceutical influences, patient advocacy groups, public funding bodies etc. - but the regular, very ordinary way in which non-medically involved persons make decisions regarding the sick people around them. It struck me that when patients were talking to me about disbelief, invalidation, malingering and all the rest of it, what they were commonly referring to was the disbelief of their neighbours, their children and their friends. This scepticism, the scepticism of the 'man in the street', has not been discussed much within philosophical circles. Perhaps this is because it is so messy, so fraught with caveats, so difficult to pin down. Perhaps also because it is considered metaphysically unsophisticated and consequentially unimportant. Or maybe because philosophers consider this to be sociological or an-

⁴⁰⁸ Some phenomenology of illness notwithstanding (see p. 89).

thropological terrain.

My position, as I have already begun to develop in this chapter, is different. The views of non-medical individuals are of great importance in relation to contested diseases, and these views are informed by philosophical standpoints about causality, disease and the body, no matter how unconscious or hidden they may be. It is these standpoints I would like to unearth and hold up as important factors in the happiness and coping ability of those of us who suffer from what I have termed contested diseases.

Being seriously ill with almost any sickness compromises you in a multitude of ways: you cannot do some of the things you used to be able to, or you have to do them in a modified way; your symptoms squeeze and constrict what you are able to focus on, minute by minute; the financial costs of healthcare, special arrangements and income lost by jobs you are no longer able to do adds up and constrains the material aspects of your life...the place you live in becomes ‘a world of negotiation, of helplessness, of avoidance’.⁴⁰⁹ But it also compromises *your person*.⁴¹⁰

Chronic illness transforms an individual’s self-concept, their idea of who they are and why they are, and the reactions of others in their immediate social environment are important shaping factors in this process. Carel writes:

‘Because it alters one’s relation to the world, illness can expose not only the limits of human experience but also the biases of an environment. The moment a par-

⁴⁰⁹ Carel, H. 2016b, p. 77

⁴¹⁰ Many studies have argued that an individual’s sense of self is severely altered by chronic, contested illness. For instance, Whitehead’s work showed that patients with chronic fatigue syndrome found their identities completely reconstituted and Clarke and James argued that patients expressed a severe loss of self-esteem as a result of their illness: Whitehead, L. ‘Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis’ in *Social Science and Medicine*, 2006, Vol. 62, pp. 2236-2245; Clarke, J. N. and James, S. ‘The radicalized self: the impact on the self of the contest nature of the diagnosis of chronic fatigue syndrome’ in *Social Science and Medicine*, 2003, Vol. 57, pp. 1387-1395.

ticular environment ceases to be familiar and becomes hostile, one is required to reflect on that environment'.⁴¹¹

Here she is talking about a person's physical surroundings - the way in which stairs become truly visible only once we struggle to ascend them - but it is just as apt a description the permanently altered social relations that come with being ill. Likewise, once this change occurs, it becomes easier to see the biases of this particular environment, in this case not uneven surfaces or previously unacknowledged distances but the unconscious systems of appraisal used to weigh up the validity of another's experience as related by them to you. Or, to put it another way, the structures by which we - ordinary, non-medical individuals - establish epistemic credibility in relation to illness become most clear once tested by an unusual, borderline phenomenon. Fibromyalgia is one such case.

Strangers, acquaintances, friends, family

The first thing to say is that, fairly self-evidently, responses to contested illness vary between individuals. There is no one, universal reaction. There are, however, certain themes that emerge and certain features of a fibromyalgia patient that seem to provoke. These are, as might be expected from the above discussion, the inconsistency and strangeness of symptoms, the distance between what is being said by a patient and what they look like, the lack of a plausible-sounding and medically endorsed aetiological explanation and, in light of this, the growth of scepticism and suspicion of malingering, no doubt exaggerated by the ongoing and pejorative public discourse around welfare payments.

It is perhaps not surprising that patients reported that strangers were the most like-

⁴¹¹ Carel, H. 2013, p. 350.

ly to regard their condition as illegitimate. Confrontations were common in relation to fibromyalgia patients exercising their rights as disabled individuals:

‘I’ve had stand up rows in car parks before. People go you can’t park here and I say why not and they go you’re not old enough to have a blue badge or you can’t have a sports car and a blue badge. And it’s like really, what does disabled look like? They just have a picture in their heads and it’s not me’.

This ‘picture in their heads’ of illness is something I developed above as ‘recognition’ and was commented on by many of my respondents. For example, one told me:

‘I’ve got a disabled parking badge and I’ve been told ‘why are you using your mother’s parking badge or your grandmother’s parking badge?’ I tell them it’s mine and they say “well you don’t look sick”’.

Often, patients believed the problem not just to be that they did not look ‘ill’ enough to meet other people’s criteria, but that these people only saw part of their story. They saw them on a good day, or a good part of a day. They were not witnesses to when they got home and crashed:

‘If someone sees you getting out of the car and you’ve parked in a disabled space and they look at you because you’re walking and they have this idea that you have to be about ninety and in a wheelchair. Society judges you because what they don’t see is that if I’ve gone into town and had a little wander around the shops, I’m struggling to get back to the car because I’m absolutely worn out’.

These comments get to the heart of what I am trying to say in this piece about expectation and recognition and all the coded ways we appraise those around us, and how this intersects with other conceptions about fairness. We are happy to give extra rights, such as a blue badge, to those who we believe deserve it and what's more, *look* as though they deserve it. The old, the frail, the wheelchair-bound. Something in the minds of a lot of people pricks up at the sight of a young, healthy looking person parking in a disabled space. We do not associate what we are seeing with potential ill health and instead reach for another explanation: that this person is trying to game the system, that they are unfairly benefiting from the generosity and kindness of others.

It is not just complete strangers who hold these views. Given more information, the name of the diagnosis, more regular encounters with the patient, we might expect to see a change in perception. But for some people this change does not occur and they remain suspicious of the motivations of fibromyalgia patients. For instance, one sufferer relayed the annoyance she felt that she her neighbours talked about how she 'claimed' to have fibromyalgia, but was in fact 'just lazy'. Some spoke about the period following their diagnosis, when acquaintances seemed to recede into the background and lengthy friendships faltered. One patient said 'I did lose most of the friends that I had'. Another told me 'I've known people for more than 30 years and as soon as I became ill they all disappeared'.

It would be wrong to ascribe this shrinking of a patient's world entirely to prejudice. Fibromyalgia, like most chronic illness, restricts an individual's ability to participate as fully in most activities as they did before, and friendships often require effort to maintain. Thus it may be as an unfortunate side-effect of their condition, rather than solely on the basis of stigma, that patients find their social lives dramatically transformed by illness. As the following story demonstrates, balancing ordinary seeming occurrences such as a night out with taking care of your body can be fraught with difficulty:

'I'm meant to be going out with a girlfriend tonight, out into town, you know dancing and all the rest of it, and I absolutely love dancing. Now the worst flare-up I ever had was after a hen do, and as you do we stayed out until 5am and I was wearing big heels and I was in pain so I was actually drinking while taking tramadol which I probably shouldn't have but I did. And so I was fine. But I was sore the next day and it got worse and worse and in the end I was in bed for four days. So now I'm actually scared, I don't want to go out tonight and I've put it on hold, I've just said I don't know if I can, it's hard to say to her that I'm scared of going out dancing because I don't want to be in bed for days. I think if I were to say I'm going to have a month where I just recoup and all the rest of it then I'm sure I'd never go out again. It's like a vicious circle. If you give up then you will just end up staying in all the time'.

This story neatly and sadly summarises the dilemma that patients find themselves in: go out and suffer heavily for it or turn down the invitations until eventually they stop being issued. For some, it is just too costly for them to go at all:

'Friends want to go out for birthday parties and stuff, but I don't go any more because I don't know what I'm going to be like. I've been to places and fallen over while I've been there and then can't get up. Life is very limited'.

So it would seem that in most cases, the reduction of a patient's social activity is a mix of both people who were previously friends dissipating and the unfortunate realities of the illness itself.⁴¹² Some groups are better able to make allowances

⁴¹² The difficulties of maintaining a social life whilst suffering from fibromyalgia are discussed here: Arnold, L. M. *et al* 'Patient Perspectives on the Impact of Fibromyalgia' in *Patient Education and Counselling*, 2008, Vol. 73, No. 1, pp. 114-120.

than others. For instance, one patient spoke with me about their experiences with motorsport:

‘It was part of my life before. After I discovered I had fibromyalgia, the rest of my friends that weren’t in motorsport walked away, apart from one person. Motorsport accepted me. It was a case of, I’m too poorly to be allowed trackside, but there were other roles that I could do’.

This respondent now works as an environmental scrutineer who monitors track noise, and thinks she is a good example of how both sides of a post-fibromyalgia relationship can make allowances in order to maintain and build social interactions.

In some cases, however, the situation is not so ambiguous as it may be with friends and strangers. With those closest to us, most often our families, the chance to skirt around issues of belief, to avoid telling a patient ‘what you really think’, is not there. Most of us live lives in close quarters, with little room to hide our opinion about certain circumstances. In other words, within a household it is a lot harder to conceal or disguise your feelings, and sometimes this comes to the fore in hard to handle ways. Relationship breakdown and familial estrangement are common fall-outs from fibromyalgia. Trying to tease apart the relative weight that beliefs about the illness, the strain of living and looking after a sick person, the financial and social impoverishment that illness can bring and the ‘ordinary’ collapse of partnerships that can occur in any relationship is a difficult analysis to undertake. It would certainly appear, however, that in many cases the lack of sincere confidence in a fibromyalgia patient’s symptoms and motivations leads directly to the fragmentation of previously solid networks. At the extreme end, you find situations like that experienced by this patient:

'I suffered domestic abuse at the hands of my daughter. She didn't believe I had fibromyalgia. She didn't understand that it was a condition that varies. She really did not grasp that my condition can fluctuate. She would tell me, in her words, that I was "scamming off the government". She would pin me in the corner of my kitchen, hurling verbal abuse over at me, that I was lying, that it was all in my head, that I was sick in the head and needed to be locked away from normal people'.

In other cases it was their parents who disbelieved them, or their partners, but the central points expressed remained the same: doubt that fibromyalgia patients were telling the truth, the sense that they had some degree of control over their health situation and general embarrassment at their condition. For instance, one patient's mother refused to hold her walking stick for her because she was concerned about what others would think while another's daughter said she didn't think her mum was a good role model because she was 'a cripple'. A patient described to me how she hid aspects of her condition from her parents because she was afraid of what they would think:

'They know about the fibro but they won't know I spent a day in bed yesterday, they just don't get it. They don't know about all the Tramadol. We just don't really talk about it. Partially it's because they think I'm being a hypochondriac and I made it up'.

The pressure placed on a household by something like fibromyalgia can be immense. Partners and children become de facto carers, and the lack of recognition that fibromyalgia has in broader bureaucratic systems means that support from lo-

cal authorities is often lacking. For example, one teenage daughter who found herself in the position of caring for her mum was offered much and given little:

‘We had a child support officer come round and they promised her youth clubs and they said they’d buy her a laptop and take her on trips and things but we never heard from them again. There’s meant to be support in place but it didn’t happen. They did nothing for her’.

Some families, it must be said, manage to cope admirably. Many partners, parents and children are compassionate and helpful, and a lot of the patients I spoke with were filled with gratitude for their assistance, both practically and psychologically. In a few cases, individuals met and built relationships with partners following their diagnosis. One husband was described as ‘so immensely supportive it’s unbelievable. He really is fantastic’, and this was not exceptionally uncommon.⁴¹³

Patterns of mistrust

The questions to raise philosophically at this point are manifold. Is it possible to say with any certainty, given the varied and complex axes on which these systems of understanding each other turn, that we are witnessing a pattern here, and a meaningful metaphysical one at that? What makes some people, for want of a better description, ‘believe’ the fibromyalgia patient in their lives where others are filled with distrust? Furthermore, isn’t an important question not just what how

⁴¹³ Both the transformative nature of contested illness on the family unit and the diverse responses family members have to sickness are covered in the following papers: Donalek, J. G. ‘When a parent is chronically ill: chronic fatigue syndrome’, in *The Journal of Nursing Research*, 2009, Vol. 58, No. 5, pp. 332-339; Jackson, E. L. ‘The effects on siblings in families with a child with chronic fatigue syndrome’ in *The Journal of Child Health Care*, 1999, Vol. 3, No. 2, pp. 27-32.

others react to fibromyalgia but what effect this reaction has on the patients themselves?

One approach to these questions is to examine what was said to me in the interviews carefully and try to apply some common-sense reasoning. All patients reported to me some form of alienation and disaffection from others following their development of fibromyalgia, and the cause of these dissolutions appeared remarkably consistent. They were, as I have already outlined, for the most part based on a foundational epistemic diminishing of the patient's explanation for their situation, exasperated by the additional effort maintaining social relations now required. It is hard to retain cordial relations with someone who you believe has brought their condition upon themselves or, worse, is fabricating illness in return for material gain, especially if doing so requires more effort on your part to accommodate the new needs of the relationship. This viewpoint, that nearly every fibromyalgia patient faces a necessary adjustment to their social world not just because of the limitations their illness imposes on them but because of the meaning that the illness holds for others, is also supported by any perusal of online forums and internet groups related to fibromyalgia. So to deny that there is any pattern at all is, I believe, severely misguided.

A slightly archaic and little recognised linguistic distinction may come in useful here. In everyday use, there is no difference between 'mistrust' and 'distrust'. That is to say, they are synonyms. However, there is a subtle dictionary distinction between them: to distrust is to be wary on the basis of experience or reasoning, whereas to mistrust is to be generally uneasy on an intuitive basis. We distrust specific people who have a history of lying to us; we mistrust every estate agent even if they personally have given us no reason to (perhaps due to several untrustworthy estate agents in our pasts).

The purpose of drawing a line between these two words is to then use them specifically in relation to fibromyalgia and my task here. I would say that in general when

people encounter individuals with contested illnesses they mistrust them, and if they are closer to the situation then this mistrust may evolve into the more *active* distrust or transform into support and solidarity. Of course what must be kept in mind is that this transition from mistrust to something else is not conducted in a vacuum: what individuals are faced with is not some purely theoretical entity, ‘fibromyalgia’, but rather the living, breathing flesh of the thing inside the body of a person they may already have reason to dislike or inclination to disbelieve. What is more interesting for me is pursuing the source of the initial *mistrust*, because it suggests that the metaphysical dice are loaded in a particular way.

In order to talk about the effect of this mistrust, I first need to talk about patients and their complicated relationship with the organic or nonorganic nature of their symptoms. Often, when in conversation with me, they seemed to not be discussing concepts at face value, but rather talking in proxies. So, when others, whether doctors or people around them, questioned the source of their pain, they took this to mean that they were suggesting it was psychological in origin. This, then, became a proxy for two tightly woven strands of resentment: that this meant that their pain was self-inflicted and that they had control over their symptoms. Furthermore, this also implies a strong degree of agency: that if they so wanted then patients could stop being ill by force of will or by changing something about their person. The overall impression was consistent with Sontag’s observation that illness is often strongly associated with psychological and temperamental inadequacy, particularly in cases where scientific knowledge is limited or ambiguous.⁴¹⁴ Comments from patients like the following that support this view were common:

‘We don’t choose to have this illness, we don’t want to be like this, you know we’d do anything really to get better. People spend ridiculous amounts of money just trying to get better, so desperate to be free from the pain’.

⁴¹⁴ Sontag, S. *Illness as metaphor*, 1978, Farrar, Straus, and Giroux, USA.

Nestled in this and similar reactions by patients is the process I outlined immediately above; the implication of choice and the suggestion of a willingness to be ill greeted by patients highlighting the lengths undertaken to be relieved of symptoms as evidence of the absolute and unalterable captivity of their condition.

Analytically, it seems unproblematic to suggest that pain may be emotional in origin but still subconscious and therefore fundamentally out of a person's control. Indeed, this is many a sympathetic doctor's position. The pain is very much real, they say, and there is no doubt that you are feeling the way you say you are, it just happens that in the absence of physical signs we believe the cause to lie elsewhere. In practice however, the majority of patients I spoke with, though willing to countenance traumatic experiences as a trigger event and accept stress as a major aggravating factor, maintained the almost unbreakable link between, for want of a better term, psychological origin and being in control of and therefore responsible for your symptoms. I say 'for want of a better term' here because it does seem as though there should be a distinction drawn between the type of 'psychological origin' patients reject. Surveys show that patients are as likely to cite emotionally painful events in their lives (abuse, breakups, etc.) as they are external physiological causes (viruses for example), but this acceptance of causality is distinct from believing that they are in pain because they are depressed, or because they are suffering ongoing emotional problems.⁴¹⁵ The point of conception, so to speak, must remain external and in the past even if psychological. A good example of this is the follow-

⁴¹⁵ van Wilgen, C. P., van Ittersum, M. W., Kaptein, A. A. and van Wijhe, M. 'Illness Perceptions in Patients With Fibromyalgia and Their Relationship to Quality of Life and Catastrophizing' in *Arthritis and Rheumatism*, 2008, Vol. 58, No. 11, pp. 3618-3626; Neer-inckx, E., van Houdenhove, B., Lysens, R., Vertommen, H. and Onghena, P. 'Attributions in chronic fatigue syndrome and fibromyalgia syndrome in tertiary care' in *The Journal of Rheumatology*, 2000, Vol. 27, No. 4, pp. 1051-1055; Häuser, W., Wilhelm, R., Klein, W. and Zimmer, C. 'Causal illness attributions and healthcare utilization in fibromyalgia syndrome' in *Der Schmerz*, 2006, Vol. 20, No. 2, pp. 119-127.

ing patient, who agreed with her doctors that overwhelmingly negative psychological incidents in her past had led to her fibromyalgia, but that this previous emotional experience did not mean that her current symptoms were psychological. ‘Something happens that just rewires your body’, she told me, ‘my body’s just wired wrongly now’.

It is worth noting that one patient I spoke with did agree with the proposition that her symptoms had an entirely emotional base and that there was little physiologically amiss in her body. My discussion with her illustrated the bind of such patients perfectly, because being apparently cognisant of this aetiology of fibromyalgia does little to change your experience of the disease. As she put it in relation to doing an activity, she felt she *knew* she could participate but this knowledge itself would not prevent the pain she felt during or reduce the soreness and fatigue she suffered afterwards. It is not difficult to see why this kind of epistemic framework is unappealing to most patients.

This problem of distinguishing ‘psychological’ from physiological is compounded by the phenomenology of the symptoms themselves, which appear to patients to be overwhelmingly biological. A lot of the issues that fibromyalgia patients have are too weird, too disconnected from their brain, too much of a physical hindrance to appear as though they could be psychological to the patients. They often seem independent of mood and more affected by biological events, i.e. the pain and flare-ups that patients report after any period of exercise or following a viral infection. It seems greatly incongruous to individuals that their symptoms are entirely psychological when they live rich emotional lives alongside varying degrees of pain and other problems. Put simply, if your condition is said to be caused by depression or other emotional dysfunction, then how is it possible to have a ‘good’ week, where you are productive and happy but still suffer from fibromyalgia? For some, trying to untangle this causal mess starts to feel futile as time wears on. As a patient told me:

‘I am now at the stage where I’m not actually all that interested in what caused it, I would just like to know what ‘it’ is and how I can get better. I am open to the idea that it may be caused by emotional factors but the very real physical symptoms seem inexplicable, unpredictable and totally random’.

I think that the strangeness and physicality of the symptoms described above suggests on an intuitive level to patients that what they are feeling in their bodies is separate to their mind, even if it may have been caused as some point in the past by emotional dysfunction. This process also serves to remind us of the casual pre-summptions we make about disease. As one patient said:

‘I can remember working with people that said they had fibromyalgia and I was thinking to myself, yes, well, what emotional problems do you have? Until it happened to me. I think there is definitely an emotional aspect to it but that’s definitely not...when my legs cramped up I knew, this is not emotional’.

It has been noted for some time that fibromyalgia patients rate their quality of life as lower than healthy controls, individuals with much more ‘serious’ conditions and doctors’ appraisals of their situation based upon clinical evidence.⁴¹⁶ Depend-

⁴¹⁶ This appears to be consistent over time and across cultures: Burckhardt, C. S., Clark, S. R. and Bennett, R. M. ‘Fibromyalgia and quality of life: a comparative analysis’ in *The Journal of Rheumatology*, 1993, Vol. 20, No. 3, pp. 475-479; Kaplan, R. M., Schmidt, S. M. and Cronan, T. A. ‘Quality of well being in patients with fibromyalgia’ in *The Journal of Rheumatology*, 2000, Vol. 27, No. 3, pp. 785-789; Hoffman, D. L. and Dukes, E. M. ‘The health status burden of people with fibromyalgia: a review of studies that assessed health status with the SF-36 or the SF-12 in *The International Journal of Clinical Practice*, 2008, Vol. 62, No. 1, pp. 115-126; Lee, J. W. *et al* ‘Determinants of quality of life in patients with fibromyalgia: A structural equation modelling approach’, in *PLoS ONE*, Vol. 12, No. 2, e0171186. doi:10.1371/journal.pone.0171186.

ing on your perspective, this might suggest a few different things. Firstly, that fibromyalgia patients are depressed exaggerators who have lost touch with the reality of their condition and do not have an appreciation of true hardship within illness. That is to say, they are not happy because *they are not happy*, which is also causing their symptoms. Or, it may point towards an under-appreciation and misunderstanding on the part of doctors and lay individuals as to the restrictive and devastatingly painful core of the disease. Or, to offer one more viewpoint, it may be that the social situation that patients find themselves in restricts their ability to develop ‘wellbeing within illness’.⁴¹⁷ In other words, they are unable to adjust to the world around them because it refuses to adjust to them. This might also explain the ‘exaggeration’ of symptoms: when we are not heard, we shout. I do not know why fibromyalgia patients appear less capable of achieving mental peace within their condition than others with chronic illness, but I suspect that the last point raised above plays a role. The psychological burden of being, to put it lightly, misunderstood, and the way in which this specific type of miscommunication (both between yourself and others - the inability to express your pain - and between your own body and your conceptualisations of it) stalks your interactions with the world cannot be conducive to positive mental health.

Organicity and legitimacy

Two main things struck me when talking to patients about the relationship between organicity and legitimacy. The first is the abject poverty of the dualism as it

⁴¹⁷ ‘Wellbeing within illness’ is a phrase used to describe the idea that though serious sickness is no doubt a difficult experience, it does not necessarily lead to a major reduction in ‘wellbeing’, or quality of life. That it does in the case of fibromyalgia contrasts with most other chronic illnesses and traumatic events, where an unpredicted and consistent level of happiness is often self-reported following the initial effects of a negative transformative experience. It is posited that in these cases we overestimate how damaging to our happiness illness will be and underestimate our personal ability to adapt. For a discussion of this concept see Carel, H. 2016b, pp. 130-149.

is understood implicitly by most patients at providing a framework for the messages they receive from their body. This is a banal point, and one much explored elsewhere over a number of years in relation to patient experience in medicine generally and in reference to fibromyalgia specifically.⁴¹⁸

The second is that I was witnessing the frequently observed ‘stubbornness’ of patients in relation to aetiology and organic symptoms, which has often been regarded as an impediment to recovery.⁴¹⁹ The argument goes that in clinging to strictly biological explanations and refusing to consider alternate causal possibilities, patients are harming their chances of getting better because they are not addressing what some see as the ‘real’ cause of their pain: a deep underlying unhappiness. Furthermore, in pursuing treatment plans based upon false premises, they actively harm their bodies through over-medication and other attempts to alleviate their symptoms such as resting for long periods or turning to untested medicines obtained outside of mainstream medical systems. Over time, this adherence to physical aetiology hardens, becoming part of a fibromyalgia patient’s identity, the illness itself becoming a ‘way of life’.⁴²⁰

Kroll-Smith and Floyd have written about this process of seeking biomedical ex-

⁴¹⁸ For two seminal papers on the role of dualism in medicine, see Sullivan, M. ‘In what sense is contemporary medicine dualistic?’ in *Culture, Medicine and Psychology*, 1986, Vol. 10, No. 4, pp. 331-350 and Engel, G. L. 1977, pp. 129-136; Demitrack, for instance, writes about chronic fatigue syndrome and fibromyalgia that: ‘These characteristics of the two illnesses, namely, profound somatic distress in the absence of any grossly evident biological dysfunction, and their apparent close association with physical and emotional stressors has confounded the traditional, dualistic Western medical model in its attempt to conceptualize them. In a broad sense, these problems serve to frame the basic dilemma for these two conditions: What is their proper place in modern medical thought? Contemporary medical and psychiatric nosologies are most comfortable with unitary illness classifications that demand that an illness be seen fundamentally as either physical or psychological in nature’. See Demitrack, M. A. ‘Chronic Fatigue Syndrome and Fibromyalgia: Dilemmas in Diagnosis and Clinical Management’ in *Psychiatric Clinics of North America*, 1998, Vol. 21, No. 3, p. 671.

⁴¹⁹ Edward Shorter writes extensively about his view of this process in Shorter, E. 1993.

⁴²⁰ Ford, C. V. 1997, p. 7.

planations above all else in relation to multiple chemical sensitivity.⁴²¹ They label it a ‘practical epistemology’ whereby patients reconfigure biomedical logic and utilise scientific rhetoric to render their condition comprehensible to themselves and others.⁴²² They argue that these patients sit at the intersection of modernity and post-modernity, neither giving themselves wholly to a medical system which cannot explain their symptoms physiologically nor privileging their subjective experiences above all else. Propelling this process is an understandable pragmatic desire on the part of patients to make sense of their illnesses through the available and socially powerful tools they find around them.

What is interesting to me is how this pragmatism of identity-building in relation to contested illness is shaped by non-medical factors. The attribution of symptoms to physiological dysfunction despite a lack of substantial evidence is frequently explained in terms of stigma, responsibility, legitimacy and delusion, and it is the exact interactions in which these concepts crystallise that I would like to focus on.

It certainly appeared to me that in reading the literature about fixed illness beliefs and considering Hacking’s looping theory that the points of contact that were portrayed as most important in establishing this belief system were between institution (or institutional representative) and subject, doctor and patient, the diagnosis and the diagnosed.

In fact, as we shall see in the remainder of this chapter, the situation for a number

⁴²¹ Kroll-Smith, S. and Floyd, H. *Bodies in Protest: Environmental Illness and the Struggle over Medical Knowledge*, New York University Press, USA, 1997.

⁴²² An example of this in practice would be the importance placed on scientific ‘sounding’ diagnoses. See Jason, L. A. and Taylor, R. R. *et al* ‘Evaluating Attributions for an Illness Based Upon the Name: Chronic Fatigue Syndrome, Myalgic Encephalopathy and Florence Nightingale Disease’ in *The American Journal of Community Psychology*, 2002, Vol. 30, No. 1, pp. 133-148 for a discussion of the implications of different semantic choices in relation to disease names and chronic fatigue syndrome. The following paper also covers some of the same ground: Huibers, M. J. H. and Wessely, S. ‘The act of diagnosis: pros and cons of labelling chronic fatigue syndrome’ in *Psychological Medicine*, 2006, Vol. 36, No. 7, pp. 895-900.

of patients is more complicated than this. The classic Hacking loop does exist to a degree, insofar as we can trace the development of the fibromyalgia concept through its different diagnostic criteria (i.e. the ACR 1990 criteria followed by the 2010 update), the growth of patient organisations and condition-specific dialect (fibro fog and flare-up), the ‘accepted’ aetiological model and so on. Indeed, it is certainly true that you can be a ‘fibromyalgia patient’ in a way you couldn’t half a century ago.

But what is interesting to me is the manner in which it appears that this ‘identity’ is stable but also exists alongside more fractured, antagonistic conflicts over the meaning of fibromyalgia. Conflicts not with doctors or medical classifications, but with people encountered on a day to day, person to person basis. The basic premise of this idea is as follows. In 2017, a fibromyalgia patient may well have a doctor who they are happy with, who is sympathetic, willing to help and genuinely believes they are ill and in need of medical care. They may subscribe to a conceptualisation of their illness such as that promoted by Yunus, which affords them an adequate explanation of what they are feeling in somatic terms. It may be also that they have friends in the patient community with whom they share their experiences and whose companionship allows them to feel comfortable and legitimised in their symptoms. Now, in this scenario, the relationship between patient and category is static and benign. The real friction between categorisation and self-concept occurs outside of these institutional frameworks. It happens in car parks and kitchens.

Because if patients are prone to taking ‘psychological origin’ as a proxy for a wide range of other, negative inferences, even if this is not what is meant by the doctor who suggests it, then this chain of reasoning could be expected to be prevalent across the population.⁴²³ Which means that in terms of categorical negotiation,

⁴²³ Survey data on lay perception of fibromyalgia is lacking, but qualitative reports from patients about their interactions with others in this research and elsewhere would seem to support this statement.

fibromyalgia patients find themselves grouped not necessarily by their actual diagnosis, but by where that diagnosis leads: so they are categorised as individuals in control of their symptoms, as malingerers, as emotional unstable and so on. To react to this by doubling-down on a categorical definition that centres around physiological dysfunction makes perfect sense, as the inferences from this are the exact opposite: no control of symptoms, understandably emotionally distressed as a result, entitled to both social and financial benefits.

The vital loops then are not between individuals and institutions but between people outside of such structures entirely. To simplify this, it is not just that fibromyalgia patients tend to prefer biological explanations in the clinic, it is that to exist in a society that so quickly makes the leap from ‘psychological’ to ‘accountable’ as someone with fibromyalgia becomes unacceptable to our sense of self if we do not postulate an understanding of the disease and of ourselves which promotes an organic base or physiological process over and upon emotional factors. This then, is the fallout from the mistrust of which I outlined above: the feeling that others around you encounter your disease in a certain way and the ultimate necessity of proving them wrong so that you can continue to be an individual who has been struck down by circumstance and not by a malignant force of their own making. Is this process dynamic? A central tenet of Hacking’s distinction between interactive kinds and indifferent ones is that the former not only get changed by their categorisation but that this then leads to a change in the way they are categorised. In this way, the category ‘wanders’. With fibromyalgia and the interpersonal (rather than institutional) loop I have described above, I would argue that dynamism is in evidence. The attitudes of non-medical persons that patients face, as described in this chapter, pressure them subconsciously towards particular explanations of their condition and to act in certain ways as a result (whether it be ‘wearing a mask’ because you don’t think other will understand or pestering the doctor for more tests). They also lead the patient to conceptualise not only their condition in a particular

way that diminishes stigmatising inferences but also to reconfigure their entire life history.

In turn, the solidifying of illness belief and the alienation felt by patients fuels community action and ‘oppositional consciousness’, leading to public information campaigns and fundraising activity.⁴²⁴ One aim of this politicisation of the disease is to increase biomedical research, but another key objective is to affect attitudes, to change the perceptions of those who fibromyalgia patients encountered pejoratively at the beginning of this process.⁴²⁵

Thinking back to the last chapter, I believe that it is by the examination of these interactions that we can make the most sense of Tekin’s pursuit of mechanism within Hacking. That is to say, she poses questions about the nature of the selves who are being ‘made up’, and here I reply that in the case of fibromyalgia a major factor in a patient’s ‘loop’ is the extent to which they can balance their self-concept

⁴²⁴ I have borrowed this term from feminist studies but I believe it is applicable here (and it is often used in relation to health movements): ‘before members of oppressed groups can act collectively, they usually must develop an oppositional consciousness. That is, they must come to see themselves as members of a group, regard their life situations as unjust, find a common interest with other members of the group in opposing that injustice, consider the injustice due to structural inequalities, and believe the injustice can be diminished or ended through their collective actions’. See: Groch, S. ‘Free Spaces: Creating Oppositional Consciousness in the Disability Rights Movement’ in Mansbridge, J. and Morris, A. *Oppositional Consciousness: The Subjective Roots of Social Protest*, 2001, The University of Chicago Press, USA, p. 65.

⁴²⁵ This attempt to ‘change minds’ occurs across plenty of other controversial, mostly mental, conditions and is supported by the fact that in some cases legitimising conceptions of illnesses without overwhelming scientific support have ‘caught hold’ of the public mind (for example the transformation of depression from personal failing into physiochemical imbalance). This is supported by survey data, for example: Furnham, A. and Telford, K. ‘Public Attitudes, Lay Theories and Mental Health Literacy: The Understanding of Mental Health’ in L’Abate, L. (ed.) *Mental Illnesses - Understanding, Prediction and Control*, 2012, InTech, doi: 10.5772/29413. Though some, such as David Healy, would argue that this process is driven largely by pharmaceutical manipulation and agitation, I would suggest that in contested illnesses (such as the ones discussed in this thesis) this occurs in tandem with patient movements rather than as a dominating factor. Both groups want roughly the same thing - a responsibility absolving, stigma reducing, biomedical explanatory model of disease - though for admittedly very different reasons.

against the various pressures exerted upon it by their surrounding social environment. Some do this by accepting their (and other's) conceptual ignorance of fibromyalgia, but many are unable to do so, or feel that doing so would delegitimise their pain and leave them at a disadvantage not just in terms of personal validation but also in relation to obtaining the sick role and its attendant benefits.

I asked then (in Chapter III) 'how much does the immediate social environment of an individual alter their self-concept?' and I am now in a position to say that this does not lead to glib and obvious truisms, (because I am not framing it in general terms but rather Hacking's parameters); it is instead a question that provokes fruitful results upon contemplation. Illness belief is inherently social, and though its negotiation may begin in a medical setting it does not end there. Whatever the trials and tribulations patients that I spoke to had with doctors, these were underlined and in some cases caused by belief systems about illness reinforced constantly by those around them. The recalibration of the self within illness that fibromyalgia forced upon patients was coordinated in light of their overall social situation, of which medical encounters played a relatively small part.

A site where this adjustment plays out most dramatically is often in the workplace where, as we will see in the next section, work, willingness to work and access to social security act as proxies again for these issues of self. The message is the same as here though, that it is the non-medical encounter that shapes an individual's categorical identity as much as any interactions with medical structures and their representatives, if not more so.

Work and Welfare

One strong theme of my conversations with patients was a willingness, desire and ability to work that had been curtailed by their illness and compounded by inflexi-

ble workplaces and the impression they received from others that they were regarded as work-shy or trying to game the system. This process often took place in the shadow of struggles against clunky and rigid bureaucracy to be awarded social security payments on the basis of long term sickness. Despite these issues, many of those I spoke to continued to work in some capacity. Often, it was the attitudes of others that formed the greater part of a patient's resentment in relation to work and statements like the following, where much is implied, were commonplace:

'It wouldn't occur to me not to work. I'm not sponging off the government getting benefits, I just need a bit of help. I paid into it for twenty years, it's not like I've never done anything'.

'There is no way I would have given up my salary by choice and given up a job I enjoyed doing and everything else, you don't just do that'.

'I don't want to stay at home and watch daytime television, I want to work'.

Time and time again the point was made by patients that they had always worked, had often held multiple jobs at once, that they were not 'the sort' to try and get something for nothing. Employment brings with it multiple social benefits - regular interactions with others, raised self-esteem, intellectual challenges, status - and many patients regarded it as fundamental to their identity.⁴²⁶ It also undoubtedly (and perhaps for some most importantly) serves a fiscal purpose. Without work, or

⁴²⁶ Other studies support the idea that work is central to many fibromyalgia patient's self-concept: Henriksson, C. M., Liedberg, G. M. and Gerdle, B. 'Women with FM: Work and rehabilitation' in *Disability and Rehabilitation*, 2005, Vol. 27, No. 12, pp. 685-695; Löfgren, M., Ekholm, J. and Öhman, A. "A constant struggle": successful strategies of women in work despite FM' in *Disability and Rehabilitation*, 2006, Vol. 28, No. 7, pp. 447-455.

with reduced working hours, patients with fibromyalgia find their lives are more restricted financially and their reliance on others greater. Particularly bristling for some is the idea that they should be grateful they no longer have to work, or that they can now work part time:

‘I get remarks like “oh you’re so lucky working part time” and I think well I used to bring home two and a half grand a month and now I bring home eight hundred pounds. That’s not lucky, that’s not good. I’m doing a job I don’t even want to do because it’s the only thing I can get with those hours’.

‘I can’t tell you how badly I would love to be working outside of the home but it’s just not physically possible...not only do you miss the money that you would be making but you miss the social interactions of speaking with other adults and you know, being out of the four walls of your home. People don’t look at it that way, they say “oh she’s lucky, she doesn’t have to work, she gets to sit at home on her butt”. I don’t want to sit at home on my butt!’

Work is symbolic for a lot of the patients I spoke with. It stands for their lives pre-illness, but also for evidence of their truthfulness and sincerity. They use their CVs as bulwarks against insinuations and accusations of laziness and scrounging. If they were indeed trying to use sickness as a way of evading employment, then why have they got no history of such evasion? Why, in fact, are their lives often evidence of the opposite: hard work over a number of years, frequently in more than one job at once? Why would they, as many do, have sought flexible working arrangements or work on a part time basis in response to the needs of their condition if their

only aim was to avoid work?⁴²⁷

Beneath the (understandable) bitterness and anger of these questions lie key aspects of illness and work in western society that fibromyalgia patients collide with: justice and fairness. What frustrates sufferers is the fact that they are not afforded the same allowances as other sick individuals, despite feeling strongly that they are just as ill, and that they have contributed the requisite amount to have earned reparations.⁴²⁸ This brings to mind the Parsonian sick role touched upon in Chapter I, that of an acceptable forfeiting of social responsibilities in case of illness in return for certain actions on the part of the sick individual themselves (i.e. following doctor's orders, trying to get better etc.).

As Steward and Sullivan have argued, the sick role is idealised theoretically around acute conditions which are characterised by 'by definitional and [patient/doctor] role clarity, consensus and harmony'.⁴²⁹ In chronic conditions like fibromyalgia where the disease is ill-defined and the symptoms inconsistent, the likelihood of recovering quickly and returning to fulfilling their functional role in society is reduced and thus key components of the sick role is compromised.⁴³⁰ It has also been argued that the temporal structure of conditions like fibromyalgia (i.e. long-term)

⁴²⁷ These questions touch upon another, older stereotype of patients with conditions such as fibromyalgia and chronic fatigue syndrome, that they are workaholics who have run themselves into the ground. As one patient told me: 'a lot of us have personalities where we are really hard workers and are always busy, you just don't stop'.

⁴²⁸ I will not have space to discuss here is the way in which fibromyalgia patients felt that welfare support is a 'earned right' that they deserved as a result of their active citizenship, but it was a theme. For examples, one patient told me they were particularly disappointed in the way they had been treated, considering that they had 'paid in tax, my parents paid in tax, my grandparents paid in tax...'

⁴²⁹ Stewart, D. C., and Sullivan, T. J. 'Illness behaviour and the sick role in chronic disease: The case of multiple sclerosis' in *Social Science and Medicine*, 1982, Vol. 16, No. 15, p. 1397.

⁴³⁰ This is a longstanding criticism of Parsons' theory. See: Segall, A. 'The sick role concept: Understanding illness behavior' in *The Journal of Health and Social Behavior*, 1976, Vol. 17, No. 2, pp. 162-169.

undermines the exemption from certain social responsibilities that the sick role provides because this exemption is predicated on a temporary suspension of ordinary duties rather than one conducted on a permanent or semi-permanent basis.⁴³¹

The difficulty of accommodating their experiences into the confines of the traditional steps of the sick role does not, however, prevent patients from attempting to do so and from feeling frustrated when they find they are unable. It has been suggested that this is ordinary illness behaviour, as the sick role narrative of restitution is the dominant reaction to disease and few other options are presented to patients as viable or natural responses to falling ill.⁴³² Therefore, regardless of its applicability to their condition, individuals with fibromyalgia will pursue this course of action.

This is evident in the long search for a diagnosis that was undertaken by many (expanded upon in the next section) and in the understanding patients had that recovery was expected of them. Unfortunately, this clashed with the knowledge most patients felt that they had or had gained, which is that they were unlikely to ever make a full recovery from fibromyalgia. The ambiguity of their disease and the impotence of treatment programmes also contributed to the difficulty patients had being afforded the social gains of sickness they felt were rightfully theirs.

In regard to the patients I spoke with, the real tension seemed not to be that they had failed to fulfil their end of the bargain (as it were), but rather that they were attempting to benefit from the sick role without being regarded by many as ill at

⁴³¹ Radley, A. *Making Sense of Illness: the Social Psychology of Health and Disease*, 1994, Sage, UK; it might also be worth noting that ongoing changes in patient behaviour, the economics of health and wider society has cast doubt on the continued application of sick role theory to acute illness: Bury, M. *Health and Illness in a Changing Society*, 1997, Sage, UK, p. 106; for a more extensive discussion of these trends, see Burnham, J. C. 'The Death of the Sick Role' in *Social History of Medicine*, 2012, Vol. 25, No. 4, pp. 761-776.

⁴³² Robinson, I. 'Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis' in *Social Science and Medicine*, 1990, Vol. 30, No. 11, pp. 1173-1186

all, or ill in the right way. The fact of the matter is they had all received, however belatedly and reluctantly, a diagnosis from a medical professional, traditionally the key to unlocking the sick role, and yet many still struggled to access its benefits. Clearly, it is not true in any straightforward sense that doctors are the only gatekeepers of the privileges of illness - other factors are in play too.

Partly this can be explained by the favouring of physical symptoms within the sick role, and the sense that only biological dysfunctional or traumatic (in the original sense of the word) injuries are sufficiently amoral to be granted special status.⁴³³ Psychological conditions raise the spectre of personal responsibility and, as we have seen, fibromyalgia sits uncomfortably athwart these two porous categories. Research such as Glenton's has shown that the presumed clear distinction between physical and mental disease has particularly deleterious consequences for individuals trying to access the sick role whilst suffering from conditions that do not align neatly with either grouping.⁴³⁴ The words she writes about back pain could be easily adapted to the case of fibromyalgia:

'While the expectations of the sick role are particularly inappropriate for the back pain sufferer, these expectations are still very much present among back pain sufferers and their surroundings. Rather than challenge those concepts about sickness and suffering that appear to be tied to the delegitimisation of their experiences, the back pain sufferers...try to fit into the system by striving to live up to the expecta-

⁴³³ Grey areas exist (e.g. hangovers) but these are mostly uncontroversial.

⁴³⁴ The visibility and consistency of symptoms are also posited as factors unconducive to success in obtaining sick role status in chronic back pain (Glenton's case study): Glenton, C. 'Chronic back pain sufferers - striving for the sick role' in *Social Science and Medicine*, 2003, Vol. 57, pp. 2243-2252; it is worth noting alongside this Goffman's description of the stigma of 'character blemishes' - weakness of will, deception, dishonesty etc. - is applicable here. Patients who find the sick role withheld from them are often motivated further in their pursuit by fear of being falsely categorised and finding themselves on the receiving end of such stigma. See: Goffman, E. *Stigma: Notes on the management of spoiled identity*, 1968, Penguin, UK.

tions of the sick role'.⁴³⁵

A further aspect to this problem is the simple observation that diagnoses are not a monolithic entities: they come in many shades and whilst medical legitimacy may inform social legitimacy, it does not do so in a blanket fashion. Stigmatised, under-determined diagnoses like fibromyalgia lack the credibility of other medical labels. As one patient told me: 'fibromyalgia itself as a name has developed quite a stigma because of so many years of being considered a, quote unquote, "trash can diagnosis"'. For conditions like fibromyalgia, the centrality of the doctor/patient relationship to the enactment of legitimisation in the sick role is called into question because being given a stamp of approval (of sorts) by a medical professional is not enough.

Beyond the diagnosis

A diagnosis offered by a doctor is just one node in a larger network of acceptance. I am talking of the broad bureaucratic structures that surround a patient - their workplace's attitude to illness, the decisions made by social security services and, if under a system like that in the US, the judgement of health insurance companies. All of these are interrelated to some degree, and all work to different parameters of disease. So it may well be the case that even though their symptoms are verified by a physician and a diagnosis is proffered, the patient is unable to take time off work because their employers do not recognise their condition or they find them-

⁴³⁵ Glenton, C. 2003, p. 2249; I find that arguments like these convincing enough to justify my use of the sick role in relation to fibromyalgia, even in light of the numerous critiques that have been put forward against it.

selves without care because their insurance does not cover them.⁴³⁶

The patients I spoke to had mixed experiences. Some, like Samuel (who I described in the first section of this chapter), felt that they had been forced out of their jobs. They found themselves caught in a bind: their condition made work harder for them and made them less appealing to their employers and so reduced their workplace capital significantly, often to the point of being made redundant or being removed in some other way (Samuel for instance was forced to leave his job on a technicality after his driving licence was revoked due to his seizures), but their sickness was not taken seriously enough for them to achieve the concessions we might associate with other diseases. Thus their ability to renegotiate their workplace position was severely limited. The protection of human rights legislation from dismissal or discrimination on the basis of disability was not utilised by any of the respondents I spoke to, possibly because of ignorance or the lengthy and costly procedures involved, although one was able to retain her position after union involvement and a tribunal.⁴³⁷

Some patients secured favourable adjustments in their terms of employment, either by going part-time or reducing their workload. Those that were able to do this in my sample tended to be the ones who had been working at the same place for a significant amount of time:

‘Work are very lenient with me and they have supported me all the way through, but they have seen me from start to finish. They’ve seen that I have gone from someone who’s been healthy, active, jolly, the lot, to someone who sits at her desk

⁴³⁶ Dumit, J. ‘Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses’ in *Social Science and Medicine*, 2006, Vol. 62, pp. 577-590.

⁴³⁷ These are common barriers to individuals acting upon their rights in a western disability/workplace setting: Tompa, E., Scott, H., Trevithick, S. and Bhattacharyya, S. ‘Precarious Employment and People with Disabilities’ in Vosko, L. F. *Precarious Employment: Understanding Market Insecurity in Canada*, 2006, McGill-Queen’s University Press, pp. 90-114.

now, does as much work as I can before I know I'm going to fall asleep or start lagging or not be able to get done what I need to get done, having regular rest breaks and things like that. So they've seen the transition'.

The point could be made that it is the case with nearly all workplace disputes that longevity plays an important role, but what I'm interested in is the specific view of disease presented to employers in the quote above. The patient feels that the salient point here is that her colleagues were witnesses to her transition from health to illness, and that they have therefore alternative evidence to the myriad ambiguities present in fibromyalgia with which to arrive at a judgement. Their sympathy and accommodation is enacted on the basis of the patient's visible transition from one state to another.

These allowances are not afforded to fibromyalgia patients trying to find new employment; without a view of their previous self in the collective minds of their coworkers, they are much more likely to be regarded with suspicion. Observing a patient 'from the beginning' provides those around them with a counterfactual to their illness: it prevents the explanatory void surrounding their symptoms leading necessarily to distrust. In short, seeing a patient transition from one type of person to another, one full of energy to one who is lethargic, provides another form of evidence. Their symptoms may be inconsistent and vague now, but they still represent something significantly removed from how that person was before.

Outside of work, patients reported to me that they struggled accessing welfare payments.⁴³⁸ Many, as previous earners and breadwinners, found the process humiliating. A common complaint was that the way in which incapacity is 'tested', i.e. established as legitimate, did not align well with the way that fibromyalgia is. Personal assessments based upon ability to do simple tasks and verbal reasoning, as

⁴³⁸ This is not unusual for patients with fibromyalgia and similar conditions: Dumit, J. 2006.

well as unconscious (or perhaps conscious) bias due to the appearance of the patient, do not take into account the inconsistency of fibromyalgia symptoms or the effect exertion has on patients in the medium term:⁴³⁹

‘Because of the way they word the forms it’s very difficult to explain to them that it is not always about what we can do at the time, but how it affects us afterwards. If we were to go and do an eight hour day when we’re on our feet all day, next day we’re not going to be able to move. They don’t allow for that kind of disability. In their eyes a disability can be seen and it’s immediate and if you take painkillers that should be the answer to everything’.

What emerged during my conversations with sufferers about social security was the strong impression that disease and its debilitating features are defined both functionally and cynically by government organisations, at least in the eyes of patients. They felt strongly that the inconsistency of their symptoms and the lack of biomarkers devalued their diagnosis and gave an inch of disbelief to individuals looking to take a mile:⁴⁴⁰

‘When I went for a medical, the person that I saw said that I made “adequate eye-contact”. This person in actual fact did not look at me once during the entire

⁴³⁹ The wholly functional assessment procedure (divorced from actual condition and focused entirely on its effects) employed by government contractors has been criticised on this basis and others: McCartney, M. ‘Medicine and the Media: Atos and changes to disabled people’s benefits’ in *The British Medical Journal*, 2012, Vol. 344, No. 7844, p. 30.

⁴⁴⁰ This is echoed by other studies: ‘When the etiology of disease is controversial...or when the existence of a disease is questioned by the medical establishment, as in the case of...fibromyalgia...it becomes difficult to access economic support from workers’ compensation systems in the event of disability’, from Lippel, K. ‘Workers’ Compensation and Controversial Illnesses’ in Moss, P. and Teghtsoonian, K. (eds.) *Contesting Illness: Process and Practices*, 2008, University of Toronto Press, p. 47.

meeting, and I was deemed fit for work’.

‘We don’t often get the benefits because they don’t believe anything’s wrong. Claiming benefits is an absolute minefield with conditions like this and a lot of people struggle’.

‘You are made to feel guilty by the way they do things and they seem to think if they see you walking about outside then you’re fine, but they don’t see when you get into the house again and collapse into a heap from just walking up the road and back. It’s really, really difficult and it is an attitude that they need to change’.

These complaints again orbit around ideas of justice and fairness, which is demonstrated not only by patient’s frustration at not receiving some form of compensation (and what might also be termed symbolic acknowledgement) for their condition, but by their anger at others who they believe to unjustly collect state support:

‘We’ve got a girl next door who is twenty-five years old, the government pays for her house because she’s got a five year old child. She does nothing but lay around the place, sunbathe in the garden and talk on her phone and it’s like why do I have to go and work and you don’t? You know what I mean? It’s madness how someone that’s healthy can get that but not someone like me’.

Some patients echoed these sentiments in a more reflective way, acknowledging the difficulty that fibromyalgia poses to what is a primarily bureaucratic, not medical, framework of administration. They considered that the acts of true malingerers had diminished the credibility of subjective reporting of illness, created a more suspicious atmosphere and made it a more difficult process for those who are legit-

imately sick:

‘I think that people who have cheated the system, have claimed when they shouldn’t, they’ve made it harder for the rest of us who are genuinely poorly. I don’t know how the system can be changed to make it fairer. Especially as you could be having a particularly bad day, you could be having a middling day, you could be having a good day. That’s never taken into account. They just judge you on what they see that day’.

Fibromyalgia patients are of course not alone in these frustrations: from the very introduction of social security provision for the sick (whether from the state or through mutual organisations), arguments about legitimate eligibility for assistance have formed the centrepiece of most debates around the just administration of the system and the larger part of most complaints against it, both in North America and the UK.⁴⁴¹ In fact, the risk of malingering was highlighted as one of the three main potential pitfalls of introducing National Health Insurance (a forerunner to the NHS) in the first place.⁴⁴² Under the current system, recent changes have seen the introduction of the Personal Independence Payment, designed to replace the Employment and Support Allowance and provide individuals with extra financial support to cover the cost of long-term health conditions. It is not linked to the ability to work or the condition itself but rather the practical effects of a disease or disability on an individual’s functional capacity.

The epistemic tension at the heart of these policies is clear: who’s assessment of

⁴⁴¹ Prince, M. J. ‘Claiming a Disability Benefit as Contesting Social Citizenship’ in Moss, P. and Teghtsoonian, K. (eds.) *Contesting Illness: Process and Practices*, 2008, University of Toronto Press, p. 31; Macnicol, J. ‘The history of work-disability in the UK, from the 1880s to the 1950s’ in *Social Policy Association Conference, 2011, 4-6th July, University of Lincoln*.

⁴⁴² Ibid.

incapacity is to be given the most weight? Or, in other words, whose definition is the most legitimate? For fibromyalgia patients who may have struggled against what they see as the undermining and dismissive attitudes of doctors, the prejudiced and hurtful views of friends and family and potentially financially incapacitating issues with employment, having their disease, or the effects of their disease, questioned on a similar but different basis in the welfare system may well contribute further to the process of solidification of illness belief I have described above.⁴⁴³

Patients are reacting in this case against rigid and false categorisation: the view that if, as some people around them believe, they have agency and control over their condition, then the seeking of welfare payments is a logical step on the path of malingering. In this scenario sufferers therefore have another incentive to emphasise the biomedical aspects of their functional impairment, because it is these components that provide best ‘evidence’ of their inability to complete tasks and detract from the idea that it is simply one person’s word against another. So, in short, although social security benefits are in theory assessed functionally in the UK, this translates into more hardening of illness belief on behalf of patients, who feel that an inability to prove the legitimacy of their disability behind its functional effects automatically places them in a highly stigmatised category, that of the benefits ‘scrounger’ or ‘cheat’.⁴⁴⁴

⁴⁴³ This brings to mind Hall and Hall’s ‘unique set of stressors’ in relation to compensation, discussed in Chapter I (p. 50).

⁴⁴⁴ This backdrop of pejorative attitudes is longstanding but has been argued to have worsened in recent years. It is particularly related to those who are seen to be unfairly benefiting from the system, e.g. individuals with subjective, unprovable health complaints like fibromyalgia: Baumberg, B., Bell, K. and Gaffney, D. *Benefits stigma in Britain*, project report for Elizabeth Finn Care, 2012: <https://www.turn2us.org.uk/About-Us/Research-and-Insights/Benefits-Stigma-in-Britain> accessed 4/3/17; Jensen, T. and Tyler, I. “‘Benefits broods’”: The cultural and political crafting of anti-welfare commonsense’ in *Critical Social Policy*, 2015, Vol. 35, No. 4, pp. 470-491.

It also leads in some cases to a false projection of their illness which more accords with what they believe welfare officers are looking for. An example from one of the patients I spoke to is illustrative here:

‘My partner and his son walked up Ben Nevis a few weeks before I met him and I thought that, that for me was a pipe dream to even consider doing that. I printed out a picture of the walk that they did and wrote on it “you can do this”...Well, in July, we went to Scotland, we went to Ben Nevis and I got a third of the way up. For me this was a phenomenal achievement, something I am immensely proud of. What’s really sad from my point of view is that I could not post my pictures on Facebook and say I did this, I got a third of the way up Ben Nevis, I couldn’t...I wanted to shout it from the rooftops but I didn’t dare because I didn’t want to jeopardise my benefits, I didn’t want people to judge me differently’.

Encapsulated in this story are many of the elements I have been discussing. By hiding her achievements within illness - her capacity to work around functional difficulties - this individual is demonstrating the pressure faced by people with fibromyalgia to present their illness in a way which accords with society’s expectations of a *truly ill* person. That is, someone whose symptoms remain consistent in their ability to incapacitate; someone who does not have fun and climb mountains but rather stays in bed and tries to get better; someone who is entitled to state aid because they are desperately, visibly sick, not because they are tired and achey.

What is interesting is the way ‘fibromyalgia’ is framed differently by patient in different situations: to their doctors, to their friends, to the state and to themselves, and though it may change shape at different sites the intention beneath the fram-

ing remains the same.⁴⁴⁵ What I mean by this is that though the precise definitions and explanations offered might vary from situation to situation, the underlying emphasis is unchanged: patients wish to be absolved of responsibility for their symptoms and recognition for their distress that aligns with their preexisting notions of sickness and justice. That the presentation of their disease does change from clinic to bedroom illustrates, I think, how individuals frame the messages their body sends them in order to achieve subconscious goals but also allows us to see the degree of ‘acceptability’ parts of their condition have in different contexts. This may well appear to be stating the obvious, but what I am trying to convey here is a sense of convergence. That is to say, when we ask questions about a patient’s epistemic stance on their illness, it is impossible to reach an answer without considering the many different sites at which that stance is challenged and renegotiated.⁴⁴⁶ What is salient here is that a patient is not afforded a binary relationship with the meaning of their illness: it is constantly in need of justification and explanation. The continued clashing of one person’s epistemology against another - the totality of *encounters* and the problem of *recognition*, leave a patient with a conception of their disease defined by what it is not. This process gestates in an individual a stronger sense of what they are going through than any conceptualisation provided by medicine and, to bring it back to Hacking’s loop, *makes them up* to a greater de-

⁴⁴⁵ For example, at a the work assessment fibromyalgia might be defined by its functional features, in the clinic by its latest symptoms, to friends often by some heuristic or other and to the individual themselves by wholesale changes to their life and their person.

⁴⁴⁶ The use of ‘epistemic’ and ‘epistemology’ in this context simply refers to knowledge-generation and its outcomes: what does a patient come to know about their condition and how is that knowledge arrived at. What weight is given to equally underdetermined explanations? Which sources of knowledge are privileged? Specifically, why do patients often end up epistemically understanding their condition in biomedical terms, despite evidence to suggest other conceptualisations are more supported? Does this decision say something about the way that the condition is experienced or does it say something about the smithy in which such beliefs are forged? I believe the answer to this last set of questions is yes on both counts.

gree than their relationship with the knowledge produced about them at an institutional level.

Care

There are two aspects of a patient's care I would like to focus on in this final section, to avoid covering the same ground as above. These are the role and relative importance of the medical encounter and the steps sufferers take to care for themselves, in particular their relation to patient-run support groups.

The first of these has been covered much elsewhere, and it is a feature of this thesis that I have tried to focus on and emphasise the importance that non-medical factors have in determining the experiences of fibromyalgia patients in relation to their conceptualisation of their illness.⁴⁴⁷ This is not to say that interactions with doctors are unimportant.

Of particular interest to me is the journey towards a diagnosis that patients go on, and how it is they come to see themselves as fibromyalgia patients. Although my sample size was very small, none of the patients I spoke to appeared to conform to Shorter and Showalter's ideas about 'fashionable' diagnoses and cultural transmis-

⁴⁴⁷ For a range of perspectives over time on the doctor-patient relationship in relation to fibromyalgia, see Hanh, S. R. *et al* 'The difficult doctor-patient relationship: Somatization, personality and psychopathology' in *Journal of Clinical Epidemiology*, 1994, Vol. 47, No. 6, pp. 647-657; Åsbring, P. and Närvänen, A. L. 'Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia' in *Qualitative Health Research*, 2002, Vol. 12, No. 2, pp. 148-160; Werner, A. and Malterud, K. 'It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors' in *Social Science and Medicine*, 2003, Vol. 57, pp. 1409-1419; Dobkin, P. L. *et al* 'Patient-physician discordance in fibromyalgia' in *The Journal of Rheumatology*, 2003, Vol. 30, pp. 1326-1334; Wasan, A. D. *et al* 'Dealing with difficult patients in your pain practice' in *Regional Anesthesia and Pain Medicine* 2005, Vol. 30, No. 2, pp. 184-192; Hayes, S. M. *et al* 2010, pp. 385-391; Clark, P., Paiva, E. S., Ginovker, A. and Salomón, P. A. 'A patient and physician survey of fibromyalgia across Latin America and Europe' in *BMC Musculoskeletal Disorders*, 2013, Vol. 14, No. 188, doi: 10.1186/1471-2474-14-188.

sion (i.e. self-diagnosis after media exposure): they often experienced symptoms for many years before being told, in many cases reluctantly and with caveats, that they probably have fibromyalgia, a name quite a few of them had never heard before.

Commonly, the diagnostic process went as follows: a patient starts suffering fatigue and joint pain, sometimes in a specific place such as the lower back or shoulder.

These symptoms continue and do not respond to painkillers whilst a multitude of tests are conducted on the patients and a variety of specialists employed to rule out other, more easily established conditions. Eventually, usually following a referral to a neurologist, physiotherapist or rheumatologist, a diagnosis of fibromyalgia is offered.

A patient told me, for instance: ‘originally we were concerned about MS, did the tests for that, couldn’t find anything. Did the tests for everything else, couldn’t find anything so we ended up at fibromyalgia’. Others were explicitly aware that theirs was a diagnosis of exclusion:

‘Some didn’t believe it, said it’s all in your head. The rheumatologist I saw just said he didn’t think it was a real disease and so what did we expect him to do about it? It isn’t anything else that you’ve got so we might as well call it that but there’s nothing I can do’.

Some were diagnosed by non-medical professionals to begin with:

‘As bad as it sounds, my hairdresser actually identified it. And said I really think you might have fibromyalgia and I went to the GP and discussed it. So she sent me to the neurologist and she said, “oh, I agree. What do you want me to do about it?” Literally in those words. And that was it. But at least I’ve got a name now and I can understand it a bit better and find more out about it. So even though I did

feel as though I'd been treated very flippantly by the neurologist, they did help me put a name to my illness'.

These quotes speak volumes about the fibromyalgia patient experience in relation to diagnosis. Often arrived at tangentially and without firm conviction, it nonetheless does offer to many patients a small degree of hope and a semblance of clarity. They have a label and a way of understanding and explaining their symptoms. However problematic this may be, it is for most patients a step up from the uncertainty and alienation of having no name at all for their distress.

Some patients do dispute their diagnosis, conscious of the methodological problems in identifying fibromyalgia. Most of all, they are not satisfied that everything that could have been done had been to locate some other, more biomedical but also, crucially, more *curable* condition. One patient in particular was wedded to the idea that she had been denied access to potential alternative diagnoses because of cost factors and thought that as she was not viewed as a legal threat to the doctors involved they were withholding treatment.⁴⁴⁸

'It's almost like it's convenient for them to diagnose it as there's no legal comeback, because I can't sue them, they don't care... You rely on family and friends and your own private money on tests with the hope that something might come up, that they might find something they haven't tested for, that they might have the cure. What if I haven't got fibromyalgia? What if it's something else? I don't know, another rare disease that may be curable or treatable? The best hope for me is that it's not fibromyalgia. But they're not giving me the option because they're not doing enough tests. It's the tests that are bothering me the most, the money and the tests'.

⁴⁴⁸ It should be noted that this patient was somewhat of an anomaly amongst the individuals I interviewed: none of the others shared her extreme antagonism towards the health service or her impression that fibromyalgia patients are treated badly by doctors primarily on the basis of cost.

What is interesting about this patient's views is how it illustrates the consumer model of patient/doctor interactions in a novel way: here the patient is acting like a consumer, rejecting the judgment of the doctor and demanding a different course of action, but their 'rights' as they see them (to undergo more tests) are being undermined by doctors who still wield the power supposedly stripped from them by precisely this kind of 'consumer' behaviour.

Other patients more faithfully enacted the 'doctor shopper' model, switching between professionals until they found one who they were happy with.⁴⁴⁹ Unlike the sufferer described immediately above, however, the issues patients had with 'bad' doctors largely revolved around the manner of the professional, rather than the substance of what they had to say. Patients sought a doctor who they felt believed them and was willing to try different therapies, even if they were ignorant or acknowledged themselves that medicine could not offer a cogent explanation or treatment plan. For example, let us look at the experience of the following patient:

'I have no fear of changing doctors if I have one that I don't feel is making sense or listening. I've had orthopaedic doctors that don't even listen, they talk over me and wanted to ignore the pain I'm feeling and pretend its not there instead of actually looking into it. I've had one that has left me in tears because he was so rude. I was standing there in massive amounts of pain, my shoulder's hurting and yet he's grabbing it and twisting it in all directions, making me scream and telling me there's nothing wrong with it. Obviously I didn't return to him'.

⁴⁴⁹ It should be noted that the concept of 'doctor shopping' can be defined in numerous ways and there is no, one universally agreed upon description: Sansone, R. A. and Sansone, L. A. 'Doctor Shopping: A Phenomenon of Many Themes' in *Innovations in Clinical Neuroscience*, 2012, Vol. 9, No. 11-12, pp. 42-46.

What is important to her relationship with her doctor is the respect with which her and her symptoms are treated. Being talked over and having her pain ignored or minimised does more to sour her relationship with a doctor than the ambiguities present in her condition. This is an example of epistemic injustice, as discussed at the beginning of this chapter: the epistemic status of the patient has been minimised and as a result she has been made to feel as if her testimony is ignored because other epistemic sources are given more credence.

A few more such instances were reported to me by patients, such as one where a patient was referred:

‘They sent me to another doctor and used the term ‘women like me’ or something. It was a very derogatory statement they had made implying it was all in my mind, kinda hypochondria’.

Other patients also complained that doctors were quick to reach for a purely psychological explanation which, for reasons described above, did not sit well with them. Though several told me that they fully accepted the psychological origin of their symptoms, this was separate from believing the symptoms themselves to *be* psychological. It was particularly frustrating for patients who were told that any mood problems they were experiencing was at the root of their pain. For them, the pain *had caused* their mood issues:

‘I know I’m not depressed but when I get an attack of all sorts of different types of pain, when I get an attack of one of those, it sends me into, well, I want to die, I feel suicidal, there’s no point in living, I can’t go on like this but then I would wake up in the morning and feel better and ready to get on with my day again. So it causes depression...I think my depression was caused by the pain’.

‘I was talking to my friend who is a physiotherapist, a recently qualified physiotherapist and he said to me “don’t let them tell you you’ve got fibromyalgia, that’s just what they tell depressed people and give you tablets for”. I just thought I’m not imagining how I feel I know I’m not imagining how I feel, I’m not that sort of person, I never have been who goes off sick or who goes to bed if they’ve got a cold, I would always keep going and they think it is in people’s heads’.

Overall though, I was surprised, given the long history of antagonism between doctors and patients presented both in the literature and online, at the number of individuals I spoke with who had positive relationships with their doctors.⁴⁵⁰ Many had formed relationships with them that were trusting, palliative and just about as good as could be expected given the circumstances. Partly this was as a result of being able to exercise choice within the healthcare system, but often a change of doctor was not necessary. Comments like the following were fairly common:

‘My GP is brilliant. I don’t go in thinking what can she do for me, I go in thinking what can we do for me. In other words, we will be a partnership. Together we do’.

⁴⁵⁰ Some examples of studies which highlight the problems that patients have with their healthcare professionals (and vice versa): Åsbring, P. and Närvänen, A. L. 2002, pp. 148-160; Werner, A. and Malterud, K. 2003, pp. 1409–1419; Bieber, C., Muller, K. G., Blumenstiel, K. *et al* ‘Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia: A qualitative and quantitative 1 year follow-up of a randomized controlled trial’ in *Patient Education and Counselling*, 2006, Vol. 63, pp. 357–366; Matthias, M. S. and Bair, M. J. ‘The Patient-Provider Relationship in Chronic Pain Management: Where Do We Go From Here?’ in *Pain Medicine*, 2010, Vol. 11, No. 12, pp. 1747-1749; Briones-Vozmediano, E., Vives-Cases, C., Ronda-Pérez, E. and Gil-González, D. ‘Patients’ and professionals’ views on managing fibromyalgia’ in *Pain Research and Management*, 2013, Vol. 18, No. 1, pp. 19-24.

'I've started with a new doctor. They will do home visits and so far they've been very good. If I make suggestions then usually they are willing to listen. I don't know if it's my background with the nursing or not but they seem to be quite obliging in that way. But it's really difficult to treat this illness'.

And, perhaps most tellingly:

'I'm very lucky, I have a family doctor who does believe in fibromyalgia'.

The majority of the patients I spoke with, then, accepted their diagnosis and it formed the basis of their ongoing interactions with their doctors and other specialists. However, the uncertainties and amorphous definitions that permeate other aspects of fibromyalgia were just as present in the clinic. Being diagnosed, for the patients I interviewed, was just one step of many towards constructing a meaningful definition of their condition and assimilating it into their present and past experiences. Even a doctor who listens to and trusts the patient may not be able to offer them much in terms of understanding what fibromyalgia 'is':

'It is a relief [to be diagnosed], but unfortunately you sit down and go, well I've been diagnosed, now what? They don't actually tell you anything when you are diagnosed, they're not helpful at all'.

'The rheumatologist did all the tests for arthritis and stuff and then said, I don't like giving this diagnosis, it makes me anxious in case I've missed something but I think it's fibromyalgia. And he didn't know anything about it. He kinda said there's not much to tell, there's not much I can do about it and that was it'.

The lack of information provided to patients, underlined it must be said by genuine clinical uncertainty, makes narrative construction more difficult. Patients look elsewhere to construct their meaning of fibromyalgia, since that offered by health-care professionals is so devoid of detail. This, combined with the impotence of the treatment plans, drive individuals to learn more about their condition from a wide range of sources. Filtering of information is necessary to avoid absorbing false information or being exploited but often patients feel like they have nothing to lose by trying something new:

‘You do tend to go online because you’re just desperate to find out things. I’m very aware that there’s a lot online, particularly from America, where people will offer a cure for it, they write books called ‘A Cure for Fibromyalgia’...well of course there’s no cure at the moment. You’ve got to sift it in your own mind and take out the relevant bits’.

‘When you’re diagnosed with something and the doctor can’t help you, you do get a little desperate looking for things, and when you see what people are offering in the way of pills and potions and this cream and that cream and all the rest of it, and the prices they are charging, and they’re not necessarily going to do anything anyway. But of course people do get very desperate when they’re in pain and fatigue and all the rest of it. You do tend to go for things’.

The bottom line is, I think, that many patients would agree with one individual I spoke with, who told me that when she was diagnosed: ‘I didn’t have a clue what it was’. Now, again, my sample size is small, but the patients I spoke to who were involved in community support groups indicated to me that it was common for a sufferer to know next to nothing about their condition when they were diagnosed. What they learnt about it they discovered through their own research and their in-

teractions with other patients, which aligns with my argument that key to the construction of meaning in this situation is the non-medical world of the patient, or perhaps more accurately their non-medically mediated world.

In my search for a mechanism behind the cultural transmission of symptoms highlighted by Shorter and Showalter I could find little to support their arguments. These patients were ill long before they were diagnosed and constructed most of what they came to know about their condition following a long period of uncertainty. No doubt framing of symptoms in light of information later learned occurs, but to say that these problems are shaped entirely and always by culture is not borne out by my research.⁴⁵¹

The centrality of the doctor-patient relationship to the production of specific symptom types, for as described by Shorter, is not evident in the patients I spoke with and neither is media exposure (at least on the face of it) or shifting medical paradigms major factors. The symptoms experienced by patients in all cases appeared to predate their meaningful assimilation of them into any kind of conceptual framework by quite a long time, decades in some instances and doctors, as discussed above, were often able to offer patients little in the way of explanation or information about fibromyalgia, which suggests a diminished element of iatrogenicity, if there is any there at all.

What deserves further investigation is whether or not patient groups contribute to the development, shape and severity of symptoms. How might this happen?

Patient groups

Showalter, as explained in Chapter III, argues for intertextuality as a means of un-

⁴⁵¹ That is to say, there seems to be a thick heart to fibromyalgia which is independent of or extremely obscurely related to the culture of the patient. Tracing lines between the individual, their symptoms and the culture they are part of was of great difficulty.

derstanding how similar symptoms appear to clot around a particular psychosomatic disease. The sum total of reporting and consumption of media surrounding a condition creates for troubled individuals ways in which to be ill - it gives them stories with which to understand what is happening to them and this subconscious interpretation causes symptoms to crystallise in a particular way. This then feeds back into the narrative: if another person feels exactly like this, then there must be some common, base cause.

In the patients I spoke to, I did not see evidence of this. Although their complaints were often similar, each had their own individual way of talking about their condition and none mentioned news reports, television shows or other media. I think this is significant. If the intense intertextuality and profound media influence suggested by Shorter and Showalter exists, then in the case of my patients its reach was hidden from me. As stated above, most of those I spoke with lived a life in limbo with regard to what they thought they had before they were given a diagnosis. Many spoke of the ambiguity of information available and the sense of living in a vacuum of information. What is more likely to have had an impact on their ideas about their condition was their interactions with other patients following diagnosis.⁴⁵²

I have included patient support groups in this section, entitled 'Care', instead of the section called 'Relationships' because as I spoke to respondents I began to see more and more that the patient 'community' was not so much something an individual with fibromyalgia automatically joins, but rather a loose network that could be utilised or rejected as they saw fit.⁴⁵³ In other words, it is more piecemeal than

⁴⁵² And by implication, following Shorter and Showalter, their symptoms (though the relationship between the level of meaning and bodily feeling is never satisfactorily elucidated).

⁴⁵³ By 'patient community' I mean: large organisations like Fibromyalgia Action UK, local support groups, online groups such as patient forums and pages on social media and helplines for those with the disease.

unitary. Most of the patients I spoke with encountered others with their condition following their diagnosis, and responses to the usefulness of doing so were varied. Some emphasised the amount of common feeling that support groups afforded and the sense of relief isolated patients got from talking to others in the same situation as themselves. Another comment that was often repeated amongst my sample, however, was the perceived negativity and defeatist attitudes prevalent throughout the community.⁴⁵⁴

Beginning with the first of these, some of those I spoke with demonstrated to me the beneficial aspects of support groups and the sharing of companionship and information therein. It was suggested to me that these groups - who meet locally and organise events across the country and are largely self-organised - play a particularly important role when a patient has just received their diagnosis and is uncertain about how to proceed. One patient, who runs a support group herself, told me that:

‘It is about giving people the support, including myself really, that you won’t get from anywhere else, because only people with the condition can understand how somebody feels. So especially for people when they’re newly diagnosed and they’re really confused and there’s nobody else to turn to and they don’t understand it, their families certainly don’t understand it, at that point it’s nice to be able to talk about it and learn a bit more about it with people who really know’.

Another said:

‘Every new person that comes, they all say they’re still alone and no-one believes them, and that no-one else understands how they feel and they feel like they’re the

⁴⁵⁴ This raised questions in my mind as to the representativeness of my sample. See Methodology, Appendix I.

only ones and they don't know how to explain it to their family. That's the general pattern of things when new people arrive'.

These quotes touch upon a point that a number of patients made to me, which is that no matter the level of support and sympathy they received from those around them, it was a relief to talk to others with fibromyalgia for the simple reason that they could truly understand what they were going through. This brings to mind the discussion earlier in this chapter about empathising with another's pain and would seem to suggest that fibromyalgia patients themselves think that there is something unique, something *other* about the symptoms they experience. What is uncertain is whether this is an intrinsic 'fact' of the condition or whether they arrive at this opinion following repeated interactions with others who never seem to understand the way that they feel inside of themselves.

Some of the patients I spoke to found that using support groups, in real life or on-line, calmed their anxieties about particular symptoms, especially those on the stranger side. In this immensely connected world, it is not that difficult to find another person who has had or is claiming to have had similar experiences to you, and that can come as a relief:

'I had this weird episode where I, this sounds really bizarre, if I tasted any food or drink my tastebuds, saliva glands or whatever, would just go berserk and so I was on the forum saying I know this is bizarre but has anyone experienced this and someone had and they didn't know what it was was. And so to go on there and get reassurance that you're not the only one to have these weird and wonderful symptoms, that's reassuring'.

'So many of the things that people talk about I go oh my God me too, it's not just

me! So I feel an acceptance and an understanding in those groups that I don't have a lot of in my real life'.

A question that these comments raised in my head was: do the negative outcomes of this process outweigh the positives for patients? That is to say, yes patients are able to find others who feel the same as them and feel less alienated as a result, but would they have been better off if they had tried to ignore the symptoms entirely rather than fixating (in a loose sense) upon them, putting them into words, talking to others about them etc.? Certainly, strange symptoms become a lot easier to assimilate into 'the disease' once it becomes evident that other people with fibromyalgia also have the same complaints. And once odd experiences become normalised as symptoms, would it not be understandable if patients began to understand every out-of-the-ordinary experience they had as a fibromyalgia symptom?

Or, to take another tack: do these quotes provide a counterbalance to ideas about intertextuality? Patients in the situations above clearly had no precedent for their experiences - no prototype, no story - and it was only through talking with others that they realised they were not the only ones who felt this way. Evidence like this appears to me to make the case that these patients are undergoing something fundamentally similar, even if bizarre.

By asking these questions we can appreciate the complicated ways that communication between patients might interact with their experiences of their body and in turn, through some obscure, little understood mechanism, actually *change* those experiences.

One further function of the fibromyalgia community that patients found helpful to them was the sharing of ideas in relation to treatment. A lot of individuals were adverse to the drug-heavy regimes suggested by their doctors and preferred to discuss with other patients what it was that had worked for them, whether that in-

volved a change in diet, a particular type of exercise or even meditation. Pooling ideas and success stories locally and online allowed patients to feel as though they were in a reciprocal relationship with each other, working together to better manage their symptoms.

Something that came as a surprise to me during my interviews, however, was the amount of negativity displayed towards the patient community by a number of my respondents. Many of those I spoke with felt that, though they had their place, online forums and local support groups could leave them feeling worse than before:

‘One girl I know went to a group but she came out of there feeling so depressed, it was so miserable, not uplifting in any form and she won’t be going back. That’s what you don’t need’.

‘There’s a lot of doom and gloom on there [the forums] and I think, oh I can’t be dealing with this today and I don’t log on’.

Some patients felt that the outcome of these attitudes, which revolved around discussions of symptoms, experiences with doctors and general tales of problems faced, was a worsening state of health. For them, the mental attitude you took as a sufferer towards your illness was critical:

‘I joined different things. It was negative, negative, negative. To the point where I was thinking good God, do something about it! Don’t just sit there and whine that you’re in bed. To be in bed all day is not an option. To me, if you lay in bed all day you’re making it worse because you’re not moving’.

‘People with fibro need to be more proactive. They need to get out of their house. I’m not saying they have to go to support groups, I just sense that their whole social

life is a little screen and a keyboard. That's not good. It's not good for them mentally, not good for them physically and possibly not good for them fiscally either'.

Attitudes like this confirmed for me more than anything the idea that beneath all the symbolic explanations and oblique theories of medico-cultural interplay, there is a strong element of fibromyalgia and similar conditions that simply *is*. Some of the patients who I spoke to, like those quoted above, had no knowledge about fibromyalgia before their diagnosis and remained open-minded following it. They tried to exercise and eat well, and above all attempted to maintain a healthy and positive mental attitude. Their experiences with doctors, whilst not without acrimony, often led to a mutual and beneficial relationship. They went online and to other patients in search of information and treatment ideas, but did so with a sceptical mind. In other words, as far as I could see, they displayed little of the characteristic stubbornness or unreasonable behaviour that one might expect to see having read portions of the literature.⁴⁵⁵ And through it all they continued to be in pain.

What my conversations with patients regarding other patients revealed as well was the degree of diverse opinions within the community. It seemed to me that some sufferers were defining themselves not just against the impressions of others, be it doctors, family or whomever, but also against what they perceived as the 'wrong' attitude towards having fibromyalgia. They did not want to give in to invalidism and they were frustrated by those who they thought of as doing so. As one patient said:

⁴⁵⁵ For an overview of some of the typical ways in which patients are characterised by physicians, see Åsbring, P. and Närvänen, A. 'Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia' in *Social Science and Medicine*, 2003, Vol. 57, No. 4, pp. 711-720. This accords with much that can be found in more informal sources such as internet forums.

‘I know that some in my group are perceived as not trying. They think ‘oh I can’t do that so I won’t work, I can’t do that so I won’t do anything. And it’s like, you know, you could do a little bit, I’m sure a call centre or something. You could answer the phone. And some will say no I can’t do it, I can’t do anything. You have got to try, you have got to push a little bit’.

Another respondent who encountered other fibromyalgia patients as part of their job said:

‘I take a lot of occupation therapy referrals with people with fibro. So obviously I cringe and keep my mouth shut because they’re asking for grab rails and things for the loo and I think for God’s sake come on, you’re not 70, you’re not 80, you’re 40 or 50 odd’.

This diversity of response and opinion led me to consider once more the pure complexity of the issue at hand here: the sheer number of variables and inputs that present themselves as patterns but may well say nothing about the experience of any one individual. In other words, the age-old problem of conducting qualitative research. Could it be the case that some of the ideas discussed in this thesis apply to some patients but not others, even though they have the same diagnosis? Of course. No doubt there is more than one way to skin a cat, just as there is more than one way to become a fibromyalgia patient and more than one way to act like one. This does not mean, however, that the words I have presented above are meaningless. On the contrary, they are infused with meaning, and in considering not just what patients say but how they say it, who they appear to be addressing, which themes they return to and the like, I think we can come to serious conclusions about not only their experience as patients but the societies which created and shaped their patienthood.

Conclusion and further questions

I have covered a lot of ground in this thesis, dipping my toe as I went in various bodies of literature from a range of fields. My hope is that the result has been a holistic examination rather than a superficial and slipshod treatment and that the material utilised was relevant. The intent was certainly to provide illumination rather than obfuscation.

At the beginning of this work, I stated that my aim was to ‘to look in detail at the philosophical context that frames the way contested, chronic illnesses are experienced and understood by patients in the early 21st century...The focus of this research is therefore to trace with greater accuracy, and more importantly greater reference to lived experience, the contours of belief and assumption which provide us with our collective map of disease’. I believe that I have succeeded in this aim. Throughout the foregoing chapters I have introduced and discussed a number of ideas which I believe help us to understand the way in which fibromyalgia patients relate to their condition and, furthermore, elucidate a general sense of our collective idea of disease, as nebulous as that may be. I have also identified and analysed those ideas which I believe to be unhelpful or distracting. Ideas such as the notion that philosophers of medicine should focus on the definition of disease problem. Though I offered arguments against this in Chapter II, let us briefly consider them again in light of this chapter.

What, for instance, can the definition of disease literature tell us about fibromyalgia? That it either is or is not a disease, depending on whose schema you employ.⁴⁵⁶ This does not resolve any controversies or offer any insight into the experiences patients have. It remains, in my view, a conceptual distraction. I think that what we can see from this final chapter is that in relation to disease we have

⁴⁵⁶ Naturalists would probably conclude that it is not, normativists that it is. Neither discuss such cases specifically.

very often been asking the wrong questions.

Instead of asking *what*, we should be asking *who, how, why* and *at what location*? Diseases are ‘defined’ constantly, most often by individuals whose definitions carry with them more consequences than those of philosophers. Truly descriptive studies of disease definition will have to give up on the false promise of universality, abandoning this edifice for work which is specific and grounded in examples. We should therefore be looking at how *diseases* are defined, not disease.

Clearly there is a huge medical component to the focus of this work, but what I have emphasised in this thesis is the extent to which non-medical factors come to bear upon patients. This is true too in relation to disease definition, for much of the literature takes it for granted that in most cases an adequate characterisation of a condition can be found (these form most of the counterexamples) without questioning either the epistemic authority on which that definition is based or asking about the diversity of opinion that may exist among the ‘definers’. Disease definition is taken to be a straightforward process enacted by a homogenous group, the philosopher’s job being to create a category which captures all of this group’s outputs. I hope that in this thesis I have shown this method to be based on false premises. Throughout this work I have also tried to demonstrate the usefulness of collapsing the categories of ‘disease’, ‘illness’ and ‘sickness’. The epistemic privileging of ‘disease’ within this schema, despite its original aims at liberation, compounds issues that patients face.⁴⁵⁷ Treating them as one and the same allows us too to switch more easily between the medical and non-medical encounter, examining all aspects of the way the disease operates (to borrow a phrase from Chapter I) rather than trying to delineate different sections of it for piecemeal analysis. We can thus talk about fibromyalgia in terms of pain receptors and welfare payments and self-doubt because they are all bees of the same hive.

⁴⁵⁷ A position I share with Annemarie Mol: Mol, A. 2003

At present the overt link between ‘disease’ and biomedical signifiers leaves patients shut out of the category and placed in another. Sociologically we would say that fibromyalgia sufferers have ‘illness’ but not ‘disease’; for the patients themselves this distinction means they are caught in a netherworld where they feel diseased but are treated as if they are not. A continued recognition and focus on the fact that distinguishing between disease as biomedically defined and sickness as experienced creates a whole category of discontented and dysfunctional patients with little to guide their experience is necessary to understand the problems of these individuals and to make their lives easier.

This work has also, I believe, demonstrated the truth behind the idea that illness presents a unique opportunity to think about our world, our beliefs and ourselves. In other words, disease is ideal philosophical fodder. The breadth and range of topics touched upon in the above discussion pay testament to this notion, and I remain convinced that there are few other topics which so aggressively force the intersection of thoughts about embodiment, mortality, causality, communication and biology. Such cases as I have discussed remain fundamentally unsolved and obscure but they are also insightful and revealing. They make us look twice, they make us consider alternatives. They make philosophers of us all.

So what is my conclusion? That it is important to think about illness from all angles, not just medical ones. That the prevailing notion of disease held loosely across the population is reductionist, mechanistic, specific; concerned with restitution; hierarchical and deferential to medical expertise in its classification; suspicious of intent and subjectivity; constructed around consistent and visual symptoms, both in the everyday and clinical senses. Individuals encountering disease have a set of preconceptions about it, and as I have detailed, a set of causal expectations. When these expectations are not met, when we do not recognise disease in an individual, then other inferences start to occupy the territory ordinarily reserved for sympathy and assistance. This mode of thinking is reflected not only in the attitudes of lay

people but also in how patients experience, rationalise and narrativise their condition. At different sites it is refracted to accommodate various aims, whether in relation to a productive, efficient workforce or a welfare system geared towards saving costs, but retains the same central features. Belief and empathy are fickle and rely upon the support of a casual matrix; simply communicating distress, against the backdrop of an explanatory void, is not enough to entitle the patient to what they feel as though they deserve. My conclusion is that the strictures of biomedical thinking are precisely that - a narrowing of vision, a tightening of the imagination. Much in the same way as blinkers prevent horses from being spooked or distracted, our modes of thinking about illness bring clear benefits, but they also act as restraints on the types of information to be considered and the credence we give to it. It becomes incredibly difficult to look at something from a different angle once you have become accustomed to seeing it in a certain way, because such a recalibration comes to require a wholesale adjustment of your viewpoint.

Leriche said that health is life lived in the silence of the organs. Fibromyalgia patients find their bodies speaking at a frequency we cannot hear. Others mistake this for silence, and therein lies the problem.

There are several questions that I did not address in this work but that as a reader you may feel have been begged. Where for example, do these prevailing notions of disease that I have sketched originate from? I covered this topic briefly in my discussion of biomedicine and with fleeting references to both a dualism and a mechanistic causality that lie beneath the surface of our worldview but truly this is a project of its own. I have only been able to outline the surface manifestations of what is an entire metaphysical edifice, no doubt with deep historical roots. My work here has shown the importance of underlying beliefs about causality, mecha-

nism, dualism and much else besides in understanding the experience of patients, but I have not had the space to uncover the origins or transmission of these ideas. Another question that is implicitly raised by my work but not addressed is the role that mass communication plays in some of the processes I have described. Does the internet and social media represent a significant sea-change in the way that patients talk to each other and relate to their conditions? Or is it just an exaggeration of previously existing structures?⁴⁵⁸ I would have very much liked to approach these questions in this thesis but, the more I investigated and pondered the role of the internet and the forms of communication it facilitated, the more I was pushed towards the conclusion that it required extensive research in its own right and a reframing of this work's key questions. I was most interested in how a patient's condition was reflected back to them by the world they encountered outside of their condition, rather than their interactions with others in their position. I think that the extent to which patient's experience was shaped by factors unrelated to the internet justify my bracketing of it in this instance.

The role of gender has been raised by many individuals I have spoken to about my research and is clearly relevant to this topic. Why is it that so many fibromyalgia patients are female?⁴⁵⁹ How is the patient experience of contested illnesses affected by gender? I suspect a convergence of biological and cultural factors would go some way to answering these questions, as well as institutional biases which lead to more women being diagnosed with contested diseases than men.⁴⁶⁰ The reason I refrained from including this discussion in my thesis is because I felt as though it

⁴⁵⁸ That is to say, there were plenty of patient movements and groups before the internet, so are we just seeing an extension of this?

⁴⁵⁹ Shorter has suggested that though there is probably a biological component, one under appreciated factor may be that women's lives are, on average, more likely to be stressful, unfulfilling and create the psychological tension that seems so often to lead to conditions such as fibromyalgia: Shorter, E.1994, pp. 87-88.

⁴⁶⁰ Not of course across all such conditions. Gulf war syndrome for instance is predominate among males, for obvious reasons.

would shift the perspective of the entire work. It is not that I do not think approaching this from a feminist viewpoint would be fruitful, but rather that I did not, when undertaking this project, have the theoretical background necessary to pursue that line of enquiry with confidence. This is another thesis for another scholar.

A fourth question might be reasonably asked. Throughout this work I have drawn upon those instances of disease that sit astride the border of legitimacy, either right on the borders of biomedical structures or else shut out but trying to get it. As such, the vocabulary I have employed around expectations and recognition is geared towards the uncanny edges of illness, those conditions that don't quite fit.⁴⁶¹ The usefulness of this exercise is, I hope, clear but it does raise the question: what of non-controversial diseases? I have written at great length about the ways in which we *don't* recognise or struggle to recognise illness and about the damage which is done when a disease *does not* meet our expectations, but what about when it does? That is to say, instead of trying to tease out prevailing notions of disease in a negative manner as I have done here, could we not take a condition that we *do* recognise and ask: what it is about this thing that seems so familiar? These are certainly interesting questions, and I would be intrigued to know how much of my analysis of contested illnesses applies to less ambiguous cases. It might be assumed that in such instances the interplay between the individual and the institution would be greater, given the more concrete aspects of the knowledge being produced about a given disease category. Whether or not this diminishes the aspects of a patient's identity constructed outside of medical interactions remains to be seen.

But these are questions for another time.

⁴⁶¹ I refrained from using the word 'uncanny' itself due to its psychoanalytic connotations.

Appendix I - Methodology

Study design

In order to collect the original data for this thesis I conducted semi-structured, recorded telephone interviews with twenty-two fibromyalgia patients, lasting between 30-60 minutes each. Twenty of these patients were from the UK and living here, one was living in the US and one was an American living in the UK. Twenty-one were female and one was male (and from the UK). They were between the ages of eighteen and sixty-five, inclusive. I tried throughout the process of recruitment and interviewing to be as sensitive as possible to the needs of the patients, in order that they would feel comfortable sharing details of their condition with me and so that my study would interject minimally into their lives.

My recruitment technique was as follows. All participants but one were self-selected: I wrote to the spokespeople for major fibromyalgia organisations within the UK such as FMA UK, discussed my project with them and asked that they kindly distribute details of my study to the support groups they worked with.⁴⁶² After that, patients were free to get in touch with me if they were interested in taking part. I received over one hundred responses, which I took on a first-come first-serve basis, only making one exception in which I invited a male to take part as he was the only man who responded to me. Patients who expressed interest were provided with a study outline and ethics sheet (see Appendix 2), and I answered any questions they had about me, my work or the project. Providing that they consented to taking part, I then arranged a time that would be convenient for them to talk with me on the phone.

⁴⁶² The exception to this was a prominent fibromyalgia blogger, whose online presence and promotion of disease awareness led me to believe they were comfortable discussing their condition and might have articulate and informed insights to share with me.

During our phone interview, after going through my ethical requirements and responsibilities and describing the process to them, I led the discussion with open-ended questions about their condition, the symptoms they experienced, how their care had been, how their family had reacted and what their work situation was. Each patient was asked, broadly, questions on the same topics. They were free to stop the interview at any time. If at any point a promising tangent developed then I allowed the participant to speak freely and let the conversation head in that direction. Towards the end of the interviews, I asked each participant if there was anything further they would like to discuss, anything they thought I should cover or whether there was something about their experience of fibromyalgia they felt deserved attention. In general I was surprised and pleased by the apparently candid nature of these talks, and of the way that patients appeared comfortable sharing sometimes intimate details of their condition.

After the interviews concluded, I sent each participant a recording of their interview, then saved and encrypted the files on my personal computer. I gave each participant the opportunity to expand upon, clarify or retract anything they had said in the interview, and several utilised this option to send me further useful details they had forgotten to mention when we spoke.

I then converted each interview to a transcript and worked from this to produce Chapter IV. Before writing this section of the thesis I re-listened to each interview and went through each transcript. It was as a result of this that I arrived at the four categories used - Pain, Relationships, Work and Welfare, Care - as these seemed to be the most salient concerns to my argument and a layered but pleasingly encompassing set of categories by which to organise my data and direct my discussion. In order to protect the confidentiality of the participants, I changed or removed all names from my work as well as potentially identifying features such as location.

When a draft of this chapter was finished, I distributed it among those I had spoken to and allowed two months for any comments, retractions or clarifications.⁴⁶³

Discussion

Many potential weak points of my study methodology will appear immediately obvious. The first is size. Twenty-two individuals is hardly likely to be representative of a large patient community. However, to contact more patients would have led, I feel, to shorter, less expansive interviews. I made a choice, therefore, to balance the need for in-depth responses with practical concerns of time consuming transcribing and organising of the data that resulted. Furthermore, on some points, I began to notice that similar themes were being brought up and that there were not wildly divergent responses to a lot of my questions. This convinced me, if not completely then sufficiently, that the number of patients I had interviewed was adequate to pass comment upon.

Sampling presents a bigger issue, I think. My aim in approaching patients through community leaders and allowing for self-selection was to avoid any chance of inconveniencing people who might be vulnerable. By simply disseminating the information and allowing patients to opt-in to the study, I think I did minimise the risk of inadvertently causing distress. However, this created other difficulties, chief among them that I was unable in any meaningful way to manipulate my participant population to make it more representative of the patient community as a whole (though mapping the demographics of this is a task in itself). I was also in the dark as to what *sort* of person would put themselves forward for a study like this, what axes they might have to grind or, indeed, whether there was a consistency to my respondents and their reasons for participating at all. The lack of information I held on the patients involved - beyond the basic inclusion criteria - caused

⁴⁶³ None of the participants wished to change their interview comments or withdraw from the study following the distribution of this draft.

me a significant amount of worry: how skewed would their responses be and in what direction? My worry was amplified slightly by the number of patients who expressed disappointment or contempt for the patient community itself. I began to wonder if I had inadvertently collected a sample of atypical patients who wanted to use the opportunity to make a point about support groups and the like.

This fear was somewhat allayed by not only the regularity of some of the responses, as detailed in Chapter IV, but also by the way in which a large portion of the rest of the data generated accorded neatly with my general sense of the disease and others like it, gleaned from my master's degree research on morgellons, extensive perusal of patient forums, online support groups and blogs, conversations with other academics at conferences and of course the medical literature itself. That I was not often completely surprised by what I heard I took to indicate a certain level of commonality to patient experiences, one which I do not wish to overstate but nonetheless one which made me more confident in the usefulness of my theorising from such a sample.

Not just the people who I interviewed but the way that I did so should be brought into question. Again my interest was to reduce the amount of stress and discomfort felt by those I was interviewing: speaking on the telephone is a less confrontational and requires less effort than face-to-face conversation, and it also grants the speaker more power to terminate the process if they so wish. As well as this, I was aware that individuals might be self-conscious about their physical condition and appearance, as well as their home, something which could distract them or put them off talking with me at all. Finally, there are practical costs involved in travelling around the country, so telephone interviews allowed me to avoid discriminating on the basis of distance, which I may have been forced to if I had chosen to conduct them in person.

Telephone interviewing also creates its own problems, however. Non-verbal communication is expressive and important and, on another note, can be vital in gain-

ing the trust of another person in an interview setting. I will never know how much I missed by choosing to conduct my interviews in the manner that I did, but as far as can be judged, I feel confident that the patients I spoke with were open and honest with me, discussing sensitive, sad and embarrassing moments in their lives. Certainly, if there was one thing which surprised me about those I spoke with, it was the even-handedness and self-awareness with which they treated their condition. This seemed to me evidence enough of sincerity.

In terms of theory, I can see room for critique of my study. I did not hang my interview structure or questions on a particular theoretical framework. However, there was present a predisposition towards certain viewpoints and my interests had congealed around particular points of discussion before I interviewed my first patient, so I think it would be incorrect to characterise my methodology as grounded theory. In other words I knew what I was looking for and I found it, the many permutations of what I found making up the bulk of the analysis presented above. So is this ethnography then? I am instantly wary of terming my work ethnographic, because it can mean many things to many people. This work is though, in a sense. My research is ethnographic in the way that Herbert Gans describes when he says 'it means being with and talking to people, especially those whose activities are not newsworthy, asking them thoughtful and empathic questions, and analysing the resulting data'.⁴⁶⁴ I take this, and my, sort of ethnography to be of the common sense variety: not overly theory-laden, willing to be proved wrong, tentative and specific where possible. But yes, it is explanations of culture - in this case the way that culture moulds our philosophical reaction to illness - that I am chasing after, and I am willing to use all and any of the tools that I find ready to hand, whether it be literature, patient forums, interviews or conversations in the pub.

This is all very well, but is it not the case that these kind of methods and intentions

⁴⁶⁴ Gans, H. in Wolfe, A. (ed.) *America at Century's End*, 1991, University of California Press, USA, p. xi.

are the preserve of sociologists rather than philosophers? It could certainly be argued that much of what I have present above would neatly assimilate into various parts of sociology of health and illness with no need to talk of metaphysics. So is it just sociology? *Do* I have a philosophical position? If so, why does it appear so obscured? My response to this is to say that, though I have sympathy with this line of thought, it strikes me that what I have largely attempted to do in this thesis is to contemplate philosophical questions in a broader, less abstracted context: what is a disease and what is not? - how do our deep-seated conceptualisations of the world affect how we experience illness in ourselves and in others? - how do historical currents, cultural deposits, relations with others, institutional categories interact and develop in us - somewhere deep and intangible - a strong *sense* of one thing rather than the other? These are, I believe, philosophical questions. They may seem general but really they are about the individual. It's just that this individual is not an idealised type, or me, or a hypothetical figure representing a viewpoint, they are the non-philosophically self-conscious among us. That is to say, they are most of us.

Still, though, I feel that something nags. I have established no particular ontological standpoint. I belong to no school. I have not engaged with my data or the literature as a phenomenologist, or a Foucauldian, or from a mechanistic causality perspective, or whatever. This is due, I think, to a combination of theoretical sloppiness and a scholarly and genuine desire to be as heterogeneous in my approach to source materials as possible. I did not take a stated position and hoped that one would emerge organically as I read and talked and listened, and this is roughly what happened. But the nebulous nature of this process and its product puts me in the difficult position of admitting that, though this work is many things, it does not benefit from the consistency, comparability and cohesiveness of a work steered more confidently by a predetermined intellectual rudder. All I can say it that I do not think it is in my nature to have done it any other way.

Appendix II - Study Ethics Sheet

Information Sheet	
This is your copy of the information sheet.	
Title of Project:	Philosophical conceptions of disease in the case of Fibromyalgia
This study has been approved by the UCL Research Ethics Committee (Project ID Number):	6584/001
Name	Harry Quinn Schone
Work Address	University College London, Gower Street, London, WC1E 6BT
Contact Details	(*For students, we strongly advise against the use of a personal contact number) Email: zcrhg20@live.ucl.ac.uk
We would like to invite	Person X to participate in this research project.
Please read the following carefully and thoroughly.	
Details of Study:	
This research project hopes to investigate the ways in which our views of the body and the mind affect the treatment of fibromyalgia patients. The aim of this work is to allow patients to explain in their own words the way in which they and others - family, friends, doctors - view their illness. By taking part in this project you are helping us to better understand the relationship between your condition and the society we live in as well as contributing to better clinical care.	
You have been selected for this study because you:	
<ul style="list-style-type: none">- are between 18-65 inclusive;- have been deemed suitable and able to participate by a leader of your patient community;- have indicated that you would be willing to contribute to this study.	
What will it involve?	
<ul style="list-style-type: none">- A telephone interview, lasting between 30-60 minutes, arranged completely at your convenience by email.- During the interview, you will be asked questions about how you live with your condition, what it means to you and how others in your life have reacted and been affected by it. Please note that some questions may touch on sensitive issues and may cause distress. You do not have to answer any questions and you can withdraw at any point.- Written and verbal consent: this is simply an email from you stating you give your informed consent and a verbal repetition of this at the beginning of the interview.	
Confidentiality	
Everything you say will be kept entirely confidential. All interviews will be recorded, and you will be supplied with a copy of this. If for any reason you are not happy with any part or all of the interview you can ask that it be removed and it will be deleted and not used in the project.	
No-one except the interviewer will have access to this data, and it will be stored, encrypted, on a personal computer.	
After the completion of the study all interviews will be destroyed.	
Total anonymity is assured in the final write-up, and no names or identifying details will be used. A copy of the chapter containing the study will be delivered to each participant so that they can see how they have helped, and also have a chance to communicate grievances or errors.	
Withdrawal	
If at ANY stage you feel as if you would like to withdraw from this study you are able to do so.	
It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.	
Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.	
All data will be collected and stored in accordance with the Data Protection Act 1998.	
Thank you for reading this information sheet and for considering take part in this research.	

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