THE SCIENCE, PRAXIS AND PERVERSION OF EVIDENCE BASED HEALTHCARE: Anticipation and Medicine

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Humanities

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SCHOOL OF ENVIRONMENT, EDUCATION AND DEVELOPMENT
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Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.
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The thesis is substantially based on the book:

Anticipation and Medicine: a critical analysis of the science, praxis and perversion of Evidence Based Healthcare

By Owen Dempsey

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The Author

I worked as a General Medical Practitioner (GP) in the UK for twenty years, with experiences of: a) the impossibilities inherent in inter-personal caring with love; and b) the contradictions imposed by increasing target-based financial incentives to practise and administer population-based screening programmes.

During that time I provided advice for the commissioning of health care services by health authorities, and gradually became aware that the (political) imperatives to innovate and buy new technology trumped any concerns about opportunity costs – it was, for example, deemed necessary to invest in new MRI scanners even if this meant taking money away from care of the older population in nursing homes. This led to a developing interest in evidence-based purchasing and a dawning realisation that effective knowledge is always inherently political, but raised questions about the function of ideology in shaping consciousness. And I began to wonder why some health carers believed so passionately in innovation even at the expense of clear opportunity costs for caring, and this begs the question: ‘Why do good people do bad things?’

I then obtained an MSc in Health Sciences and Clinical Evaluation at the University of York, published my dissertation on GP decision making around emergency admissions (Dempsey & Bekker, 2002 p18), and subsequently led and published research into the management of behavioural problems of older people in nursing homes, and the over-use of sedative medication (Dempsey, 2005b). This led to an interest in Foucault and power. I then wrote a book chapter on the management of dementia in primary care (Dempsey, 2005a). After a spell working as a GP in New Zealand, I returned to the UK and obtained a PGCE in primary care education. Subsequently I ran a weekly educational programme for GPs in inner city Bradford. Then, as a senior lecturer in Primary Care at Leeds University I developed an innovative module for fourth year medical students on ‘Medicine and the Humanities’ focusing on critical theory (the Frankfurt School), media literacy, and developing self-awareness through art and writing therapy and art criticism. I published a paper based
on this module as: ‘critical thinking synergism: medicine and the arts’ (Dempsey & Lucas, 2006).

Medically, I then focused on clinical GP work with the homeless, asylum seekers and refugees, eventually leading to work concentrating on problems of addiction and substance abuse. Increasingly aware of the importance of the role of culture and the media in shaping the beliefs of both the lay public and health professionals, I sought out further education on this topic for myself. After being allowed to attend a course run by Dr Paul Taylor on communication theory at the University of Leeds I became aware of Lacanian approaches to psychosocial critique. This led to a quest for more focussed knowledge on this topic, and for ways to critique Evidence Based Medicine (EBM) and, eventually, to Professor Ian Parker and this PhD. Marx and Lacan offer potential ways of understanding how ideologies affect beliefs and practice, and a possible answer to my question above. I have published on the biopolitics of screening (Dempsey, 2017). I have recently taken early retirement from clinical medical work, and have since undertaken training as a peace activist with an international humanitarian organisation. This has involved spending time in Israel and Palestine. I recognise that there are useful parallels between philosophies of peace-making based on an embodiment of so-called liberating love and models for inter-personal care giving and trauma care, with love, that have been developed in this thesis, and this informs my on-going practice.

It is possible that doing this PhD has helped me to work through some of my own compulsion to seek new knowledge, although, in my role as a health professional (albeit now an ex-GP) I still have a desire to know how to identify the ways in which health sciences and industries misrecognise the unknowable as if it is knowable, so that I can provoke a change in practice by restructuring the praxis of EBM. (18th March 2019)
Abstract

In this thesis I am addressing the anticipatory care paradox. This is the way in which anticipatory diagnostic interventions, such as cancer screening, applied to asymptomatic populations in order to predict and prevent future illness, are being implemented in the name of improving health but are, in fact, causing increasing harm to health itself and to the capacity to care and respond to suffering with love.

The overall argument that I am presenting is that whilst both the offer and the implementation of such interventions are warranted on the basis of an apparently objective and democratic philosophy of Evidence Based Medicine (EBM), instead these kinds of interventions are, on the whole, subjective, misleading, anti-democratic and oppressive.

I show that this is because such interventions: incite anxiety and fear that exploit desire, are fetishised both as commodities and as object causes of desire, depersonalise care-providers and ‘patients’ making it harder to provide or access interpersonal care with love, and demand excessive implementation for implementation’s sake, and may even lead to a perversion of care that harms for harm’s sake.

I do this by using a Lacanian psychoanalytic perspective on subjectivity - the formation of identities as dependent on an underlying insufficiency of self-consciousness and vulnerable to desire and anticipation. I show how subjectivities of both care-providers and ‘patients’ are formed in relation to apparently authoritative ‘offers’ of anticipatory care and treatments that determine what can be meant by the aim of such care through signifiers such as health, and doing the good. And, I show how these meanings are produced by ways-of-knowing and language in discourse underpinned, not by EBM, but by the ideologies of a) neoliberal capitalist political economy and b) the scientific philosophy of pragmatism.

I use Lacan’s structure of discourse to take advantage of the strong analogy between the structure of the capitalist economy at a social level as analysed by Marx, and the
structure of the psyche of the subject of capitalism, at an individual level, as analysed by Lacan.

I have identified a normative effective truth, used to justify anticipatory medical care, that is misleading, anti-democratic and oppressive, and that dominates health care beliefs and praxis in this important and expanding field. I have shown that the justification for this form of care is sustained by EBM’s scientific philosophy that: a) disavows the problem of the threshold between the normal and the pathological; and b) psychologises the minds of individuals, as if they are totally responsible for their beliefs, as if these are independent of social reality and processes.

**Keywords**: subjectivity; disavowal; health, Evidence Based Medicine; philosophy; science; neoliberalism; pragmatism; positivism; empiricism; economics; ethics; politics; healthcare; disease; diagnosis; overdiagnosis; medicalisation; iatrogenic harm; screening; Lacan; psychoanalysis; discourse; capitalism
Introduction

This book is a critique of the praxis of Evidence Based Medicine (EBM) as applied to population-based anticipatory diagnostic healthcare. By praxis I refer, with reference to Lévi-Strauss’s terminology as cited in Nobus and Quinn (2005 p42) to ‘the conceptual foundations, the invariable constitutive units on whose basis practices can unfold’. I analyse this form of care as a commodity in a capitalist economy because this reveals how it is used by science and politics to produce knowledge as effective truths for the meaning of ‘health’ and ‘doing the good’ that shape the subjectivities of both care providers and consumers (or care labour). It is a commodity that promises surplus life, produced, consumed and fetishised in the more or less regulated markets of capitalism. EBM is, in general terms, a code of practice for applying the findings of empirical scientific inquiry to decide what constitutes good healthcare, and as praxis it combines both a theoretical basis and practical code for application. I apply the term anticipation to medical or healthcare practices that identify individual characteristics said to predict threats to future health that can be taken in hand in advance by treatment. In this sense this mode of care is individualised. In other words, anticipation used here refers to individual endogenous internal threats posed by the individual’s entire being to that individual’s life, and it does not refer to the kinds of exogenous or environmental threats that might be posed, for example, by viral epidemics, infectious disease or poor sanitation.

In addition, by anticipatory care I refer to care that anticipates future suffering of a kind not present at the time of anticipation. Anticipation identifies a problem in advance (ante-, here, meaning before) in order to solve it, (-capere, meaning to deal with, or take in hand). It is pro-active and applied at population levels to the asymptomatic, that is, to the non-complaining individual. In this sense it is universalised. It is a screening practice that uses diagnostic technologies and criteria to identify named pathology or disease that could or should be treated, or to define risk, according to boundaries that are set by experts and are socially accepted. These screen-diagnoses, or risk measurements, then decide what treatment is needed to prevent future disease.
The kind of anticipatory care that is the object of this book includes both what is commonly described as population-based screening (such as cancer screening programmes), the introduction of controversial novel forms of mental diagnosis (such as hoarding syndrome), as well as what is often described as 4P medicine (by proponents of anticipatory diagnostic tests such as molecular genetic signature profiling for disease susceptibility) – where the 4Ps are ‘Personal, Predictive, Preventive, and Participatory’ (Rose, 2013 p343). Although molecular or genetic profiling is marketed as providing personalised diagnostic or risk data, in fact it only differentiates between populations: groups of people according to stratified and uncertain levels of future risk of disease.

The contemporary neoliberal market emphasises the desirability of this so-called ‘personalised medicine’. This is marketed as being ‘the future’ of medicine, where the emphasis will become prevention and not cure (Golubnitchaja, 2017 pp69-86). It is marketed as providing full, transparent and tailored information to the individual: a practice of care that, it claims, respects the ‘whole person’, and gives her the apparent freedom to choose, determine and create her own future.

However, a standpoint of this analysis is that this mode of population-based, but at the same time individualised, anticipatory care causes a care paradox: a form of care that is aimed at improving health but, however, is an important cause of avoidable net harm to health and healthcare effectiveness. These collateral harms include, for example, the intentional effects of treatment, such as, for example, mastectomies after breast cancer screening, the side effects of tests and treatments (adverse reactions, or morbidity), overdiagnosis (described below), opportunity costs (here, in terms of the loss of opportunity to spend money on existing forms of care because money has been diverted to pay for new forms of care) causing the degradation of service effectiveness and a reduction in availability to, or presence to, suffering, and financial toxicity.

One object or problem addressed in this analysis is knowledge itself, and a second is the existing social reality that produces knowledge.

First, I am concerned with the knowledge that warrants the praxis of anticipatory healthcare. This knowledge is derived from: a) the facts derived from EBM’s
empirical ‘scientific’ evidence, which is then b) transformed into knowledge which functions as an ‘effective’ truth. By ‘effective’ I mean that this knowledge forms, and is used by human beings to form: our sense of ourselves, and our beliefs that decide our behaviour. This is called normative knowledge because it decides what is publicly acceptable as socially and morally ‘normal’ and by default implies what isn’t.

Second, it is the existing social reality that decides how effective truth, or normative knowledge, is produced. This is the second object or problem addressed here: this is the scientific-political-economic system (the empirical ways-of-knowing that combine with ways of ordering society through capitalism). It is this system that both sets limits to, and induces belief in, this effective normative knowledge. I describe this system as neoliberal pragmatism: this is a deregulated form of capitalism and a take-over of objective empiricism by a subjective radical empiricism, an elitist subjective version of the scientific evidence that decides what is good EBM practice.

The assumptions at the heart of anticipatory care are that: a) population-based anticipatory healthcare enables early diagnosis of ‘real’ pathology or disease that can be effectively treated to prevent future suffering; and b) that it is a good thing. And, ‘is a good thing’ is the normative element of this statement.

Knowledge functions in three ways in this analysis: a) as empirically demonstrable facts, for example: paracetamol relieves pain but can kill in overdose; b) normative knowledge: essentially these are beliefs espoused by, for example, expert authority that guide how people ‘should’ (normatively) behave – these may or may not actually be empirically demonstrable or even true at an individual level as such, for example, exercise is good for you, or cancer screening is a good thing; and c) a particular kind of knowledge peculiar to anticipatory care, knowledge that is in one sense non-normative, in that it could count against care as ‘a good thing’, but is also transformed into a fact-number that paradoxically promotes anticipatory care. This third kind of knowledge is knowledge of the harm and/or scale of overdiagnosis.

The critical analysis in the thesis:

a) uses Marx’s theory of commodity fetishism to relate capitalist ideology to Lacan’s university discourse structure to draw implications for subjectivities being constructed by anticipatory diagnostic medicine;
b) considers different proposed definitions of disease to show how these can work discursively to construct (hypostatise) the concept of borderline screen diagnoses as ‘real’ cancer;

c) relates an empirical economic analysis of cost-effectiveness (C/E) to show that apparent C/E thresholds can always be exceeded;

d) shows how the indeterminacy (of meaning) of language enables the term ‘overdiagnosis’ to be used to undermine democratic decision making; and

e) draws on Lacanian ideas about caring-with-love to provide implications for subjectivities incited to excess by population-based anticipatory diagnostic medicine.

The epistemological standpoint in this thesis is based on psychoanalytic construction that focuses on producing a fall in knowledge by identifying an unknowable hole in the knowledge at the heart of, and assumed by, population-based anticipatory diagnostic medicine, as revealed by surprising contradictions inconsistent with the praxis and goals of EBM. The thesis is also an intervention that: a) reveals the gap between communicative acts and unconscious formations; b) provides explanations for why contradictions emerge and c) deduces consequences for subjectivity and the praxis of EBM.

An example of psychoanalytic construction is provided by Freud’s’ approach wherein, say, slips of the tongue are regarded as a ‘rational occurrence in their own right’ (Nobus p29), and a ‘structured emergence of thought with a specific history and a certain future’ (p29). Such unpredictable, marginal slips provide the basis for a “Freudian” psychoanalytic construction for the cause of, for example, a specific individual’s neurotic symptom that may be due to some past and repressed trauma producing symptoms and affecting psychic and emotional development. This thesis, takes as its object a specific mode of healthcare, and takes its continuing expansion despite collateral harms as a kind of symptom.

So, for example, in this thesis, by identifying contradictory meanings for the concept of disease, I have made visible the hidden normative social relations, values and the ‘hole in knowledge’ that is the unknowable specificity that marks disease, a hole elided by prevalent normative discourse and meanings. This approach is not through
the analysis of central and recurring themes as in other forms of qualitative discourse analysis, but instead finds implications from the unexpected marginal contradictions in discourse. This approach uses a Lacanian theory of subjectivity, the unconscious and language to analyse social discourse and its contradictions to identify unconscious knowledge, made meaningless and repressed from social discourse, in order to understand how and why, at an individual level some knowledge and practice is believed to be a good thing, at the expense of other knowledge, such as collateral harms.

Here, I will briefly situate this approach in relation to two other possible broad epistemologies: critical realism and social constructivism. Notice that what is most at stake here is the Lacanian notion of subjectivity. This is the notion of the subject constituted by, and in relation to, the unconscious and prevalent social discourse and norms, without any degree of self-determination or governance, and the subject desiring, but always failing to achieve, a full sense of self or identity, a desire for recognition by the discourse of the Other, as Lacan writes:

‘If I have said that the unconscious is the Other’s discourse (with a capital O), it is in order to indicate the beyond in which the recognition of desire is tied to the desire for recognition. In other words, this other is the Other that even my lie invokes as a guarantor of the truth in which my lie subsists. Here we see that the dimension of truth emerges with the appearance of language’ (Lacan, 2002a p436)

By contrast, in general terms, both critical realism and social constructivism take the human subject to be an autonomous, self-creating actor, both acting upon and being produced by orders of social events, structures and relations.

So, the psychoanalytic construction approach here is different to, for example, critical realism. Critical realism, simply put, is a method used in social research that asserts that analysis can reveal the presence and action of unobservable but real events in order to provide explanatory theories of the cause of complex social phenomena. It holds that these real events may not be empirically verifiable: ‘… in such cases, these things can only be reconstructed through retroductive or abductive inferences; arguments which move from a social phenomena to a theory which is able to account for that phenomena’ (Archer, 2016). Crucially, however, for critical realism a theory
of the human psyche and subjectivity as constituted through language and the unconscious is not necessary to explain complex social phenomena. Therefore, I argue that critical realism is not appropriate for an analysis of questions central to this thesis, that is, how and why individuals have subjectivities formed within and by social discourses and relations in ways that determine individual behaviours and beliefs in what can be assertively warranted as good practice even when they are causing harms.

The psychoanalytic construction approach here can also be situated in relation to another important broad epistemology known as social constructivism. Simply put, this contrasts with critical realism because it holds that the way individuals’ identities construct and are constructed by and in relation to social relations and norms, does not necessarily manifest anything real. In addition, as for Foucault, the individual is viewed as a product of discursive positioning and fixation (Foucault, 2004), but crucially this approach retains notions of self-determination, human agency, and of autonomous thought and the creative actor. Thus, what is produced is the confessional, subjectivised self-entrepreneur (homo-oeconomicus) of Foucault, ‘whose domination’ is conditioned by ‘his subjective participation in the act of domination’ (Esposito, 2008a p35). Social constructivist accounts ‘are less about inner desires and personal behaviours than a site where ideologies, cultural norms and institutions interweave’ (Elliot, 2001 p436). Thus, as with critical realism, I argue that as an approach this would not be able to account for the way that individuals hold beliefs in particular ideological norms even in the face of collateral harms, as if that knowledge is made unconscious or meaningless. And, so social constructivism does not have the explanatory (potentially political and emancipatory) power of Lacanian notions of subjectivity and fantasy for the ongoing excessive consumerism, fetishism of commodities, and, here, the continuing extension of anticipatory modes of health care in neoliberal capitalist societies (Fisher, 2009; Kordela, 1999; Žižek, 1989).

I won’t go into detail here, but briefly, there are other epistemological theoretical approaches used and sometimes combined with critical realist and/or social constructivist approaches in, for example, educational research, such as Cultural Historical Activity Theory (CHAT) (Edwards, 2011; Engestrom, 2009). This has evolved and been developed originally from Soviet psychological theories of the
Introduction

historically, culturally informed and mutually inter-dependent (dialectical) relations between activity (and the tools of activity), consciousness (as a cognitive process involving functional information processing units), and multiple individual and collective activities. However, this approach as with CR, and most kinds of social constructivism, assumes that individual motivations and aims can be known as if the individual can be fully self-aware even whilst his or her consciousness is being socially mediated.

The psychoanalytic construction in this thesis is based on the ‘logic of psychoanalytic discovery derived from the Peircian principle of abduction’ (Nobus & Quinn, 2005 p33) ‘… abduction is the process of forming an explanatory hypothesis. It is the only logical operation which introduces any new idea’ (Peirce, 1934). Nobus and Quinn argue that although ‘very few scientists have endorsed the value of abductive inferences’, however, ‘… the psychoanalytic conception of truthfulness is radically different from any of the traditional criteria for establishing truth, and how this psychoanalytic truthfulness chimes with the ‘fall of knowledge’’ Nobus and Quinn (2005 p34).

The standpoint of this thesis is that ‘ … ‘Being truthful’ has nothing to do with one’s efforts to represent things as they really are, but concerns the knowledge that any effort at representation is doomed to fail.’ Thus, modern science has lost its Cartesian roots in radical doubt, and as a result has rejected the idea of truth: conceptualised as radical doubt itself, error, and the constructivist effects, but crucially also necessary indeterminacy) of language itself. This is truth as material cause of subjectivity, as that which drives and provides the means for the striving to form, but always failing to wholly achieve, a sense of self and purpose through human beliefs and actions. For a psychoanalytic construction, ‘the truth of a phenomenon, action or process lies … only in its building blocks, which are made up of speech and language’ (Nobus & Quinn, 2005 p59) Nobus and Quinn go on to analyse Lacan’s paper Science and Truth (Lacan, 2002d), on the relation between knowledge and truth but I do not explore this any further here.

The principle of abductive reasoning (ibid. p31):

1. A surprising event E is observed
2. If hypothesis H were true E would be obvious

3. There is reason to believe H is true.

In Freudian terms:

1. A surprising formation of the unconscious occurs (e.g. a slip of the tongue, a dream)

2. If our psychoanalytic explanatory hypothesis were true, this formation of the unconscious would be obvious

3. We have reason to believe that our explanatory hypothesis is true

In psychoanalytic social research then, I suggest:

1. Surprising manifestations of unconscious formations produced by normative/effective social truths (that decide what is good practice) are observed

2. If our psychoanalytic explanatory hypothesis were true, these formations of the unconscious would be obvious

3. We have reason to believe that our explanatory hypothesis is true

In psychosocial research the manifestations that I have identified are ‘surprising’ because they reveal contradictions in existing knowledge and practice intent and yet these remain hidden and so cannot function to stimulate changes in practice and, so far anyway, do not lead to new effective truths (where an effective truth, here, is one that does not necessarily correspond to observations but nonetheless effectively shapes the beliefs in what can and should be asserted as good practice, and warrants assertions that guide actions, see conclusion for further discussion).

The psychoanalytic-social research in this thesis progresses by revealing potential emancipatory knowledge that has had its (potentially emancipatory) meaning suppressed. By ‘emancipatory’ I refer to the power to increase an individual’s capacity to choose between competing symbolic demands (the materiality of speech and language) to form subjectivity (albeit still being in no way capable of self-
determination as such), for example by resisting prevalent normative social truths. And, this is done so that such suppressed meanings may be revived and become effective. This is close to the idea of psychoanalytic truthfulness, the disruption of sense so that unconscious signifiers may emerge that ‘chime with the fall of knowledge’ (ibid. p34) or, in other words, makes it possible for existing normative/effective truths and their meanings to be rejected.

Lacanian psychoanalysis provides fresh insights into: a) the harms caused by EBM’s attempt to identify and specify, empirically, the unknowable border between the normal and the pathological; and b) how this attempt produces knowledge commodities (for example borderline screen cancer diagnoses, or borderline blood pressures etc.) that function within care practices to drive the search for more knowledge; and c) the way this subjectivises and oppress subjects (patients and carers).

Note that using psychoanalysis for social critique is different to using psychoanalysis in the clinic in the 1:1 interaction between analyst and analysand. In a Lacanian clinic analysis attempts to disrupt the existent sense of self or identity by provoking uncertainties through interventions that ‘… occupy a space between meaning and non-meaning’ (ibid. p32), designed to challenge and de-stabilise existing self-understanding, and that ‘… aims at re-structuring an already existing body of knowledge around its intrinsic fissures’ (ibid. p33) in order to make room for possible new understandings and identities.

However, the psychosocial intervention does not necessarily provoke a social process with a disruption as if it were an analysand. In the Lacanian psychosocial critique in this thesis different aspects of Lacanian theory are used in different chapters and these are elaborated as the thesis proceeds. The particular use of theory is driven by, for example: a) the nature of the discursive event or provocation (for example: an apparent coercion to be screened, or an apparently perverse excess of care); or b) a dimension of subjectivity (for example: caring-with-love), under consideration. Theory is then used in an analytic construction to provoke a fall in knowledge, to undermine the ‘suture’ that ties us to certain scientific effective ‘truths’ – and this becomes, in this analysis, a passion for not assuming that medical diagnostic technology is able to identify, as if an empirical fact, an individual’s biological future,
so that it can be anticipated, that is, taken care of in advance. And, the analytic construction incites a passion for *not* acting, speaking and pro-actively offering technologies of anticipation to the asymptomatic.

Also, note that there are different kinds of psychoanalysis used in psychosocial research, (for a summary see Frosh, 2010 pp204-209). For example, whilst a Kleinian approach, simply put, ‘… pursues a sense-making agenda in which everything comes together in the end’ (ibid. p205), on the other hand Lacanian analysis is distinguished, in simple terms, by ‘a deferral of meaning … to disrupt sense’ (ibid. p206) on the basis of:

a) a passion for ignorance (Nobus & Quinn, 2005 pp32-3), insisting on the necessary persistent gap between knowledge and truth, (between, say knowledge of the world as represented to us, and the world as it really is);

b) the impossibility of achieving ‘a state of full knowledge’ (ibid. p22);

c) the indeterminacy of language (for an example see chapter 4: 'Negotiating text with Lacan' in Parker; & Pavon Cuellar, 2013) – so that adequate interpretation of meaning always escapes us; and

d) an epistemological drive for more new knowledge, as the object cause of desire in our quest for identity, that always fails to satisfy.

Psychosocial critique of this kind has been used to critique a wide range of social processes, such as mental health care and diagnoses, global politics, racism, colonialism, films and literary theory (Frosh, 2010; Parker; & Pavon Cuellar, 2013). Of most relevance to this thesis is the use of critical psychology using Lacanian ideas to critique empirical psychology itself. Critical psychology critiques the oppression of individuals by the scientific-empirical psychologisation of individuals, for the purposes of psychological and neuroscientific research, as if an individual’s psyche is independent of social processes (Parker, 2011a; 2015a pp57-8). Critical psychology provides fresh insights into possible new, resistant and revolutionary identities, that identify impacts of social processes, and medicalisation on, for example: happiness, ‘If Happiness Studies and Wellbeing advocate ‘positive thinking’ ( … ‘cruel optimism’) in the face of the intensifying depredations of capital, then psychoanalysis,
conversely, makes us attend to the new forms of suffering that arise from an inability to be happy with consumer models of happiness' (Wright, 2014 p792), mental health and diagnostic processes (Parker, 1995); and the way individuals are made to feel responsible for their own mental distress (Fisher, 2009 pp16-30).

Current attempts to address the increasing harms of anticipatory EBM within the scientific framework of EBM (through for example, calls for more attention to be paid to patient values, and techniques of shared decision-making) fail to address the excesses of overdiagnosis and only sustains the over-optimistic implementation of empirical anticipatory diagnostic programmes and the empirical treatment of the psyche. EBM continues to psychologise both patients and carers. EBM and modern science fail to provide an adequate account of: a) the anti-democratic nature of unsolicited population-based anticipatory diagnostic medicine; and b) the oppressive and disingenuous hypostatisation of the concept of a border between the normal and the pathological.

Briefly, I suggest that overdiagnosis as harm is transformed into a normative fact-number because, under capitalism, it is not, as I show, valued as harm as such, so it normatively promotes instead of, as harm, working against the implementation of care. And, although it can be calculated indirectly it can never be empirically personally experienced. This means, as harm, its meaning is made unconscious. Overdiagnosis occurs when a diagnosis is made of hidden or occult or even apparently (expert defined) symptomatic ‘disease’, that indicates treatment is advised, but that will never cause an individual any problems, as far as she is concerned, in her lifetime.

However, normative knowledge, as effective truths, induces beliefs that guide individual behaviour or practice. These beliefs are formed and unformed in relation to the existing social reality, which is dominated by the political-scientific ideology of neoliberal pragmatism. And, at the same time the language of persuasive rhetoric, makes corresponding but opposite truths non-normative, or non-effective, by making them unconscious, or ungraspable as meaning anything.

EBM praxis, with its crucial assumptions of states of full knowledge, and of a psychologised empirical subject (carer and/or patient), leads to the continuing
expansion of anticipatory care consistent with a social reality dominated by neoliberal pragmatism. This political-scientific ideology, or system, is then analysed, as a problem, using primarily Marx’s analysis of capitalism that shows how the system induces some beliefs whilst making other knowledge unconscious. Lacan’s psychoanalytical theory of subjectivity is used as a tool to explain why and how institutions and individuals behave according to these beliefs, and to deduce the impact on the possibilities for caring with love.

This brings me to the six key ideas that function as sites of legitimately contestable normative knowledge production. These are the sites where the critique takes place. These are sites that reveal hidden deadlocks, that is, the impossibilities that indicate false assumptions that aggravate and produce harm.

These six key ideas are: subjectivity – what it means to be a human being pursuing, albeit ultimately unsuccessfully, a sense of self and purpose, science – one way the human being knows things about the world, health – what it means to be well or ill, or to be needing care, ‘doing the good’ – what it means to care, political-economic relations: what capitalism means, and, finally, language. I will very briefly take these in turn to indicate what I take to be at stake, and therefore contestable, in each and the relevance to anticipatory care praxis.

Subjectivity: (see chapter 6: ‘the mirror stage and alienating identity’, and chapter 11: ‘the Oedipus complex’). One component of EBM praxis, to simplify, assumes the human being is a ‘whole person’, a self-sufficient and self-creating actor who is capable of knowing herself fully. This raises questions. Is it misleading for anticipatory healthcare practice to refer to the patient as a whole person, free to create and be responsible for her own future? Is the human being a fully self-aware, self-creating autonomous actor, or can she never be fully self-aware?

I take the Lacanian standpoint on the notion of subjectivity that the subject is divided in the sense that she is always insufficiently self-conscious (Lacan, 2002c), but is driven to try to make sense of her self through social relations. Her sense of her self, her truths and beliefs, are always in the process of being formed, unformed and reformed through social relations and discourse. Therefore she is vulnerable to normative truths (persuasive rhetoric) espoused by expert authority, vulnerable to the
exploitation of her desires by the demands of commodity exchange under capitalism, and to being coerced into forms of anticipatory care. Thus, even whilst she has, to an extent, capacity to unform and reform her truths and beliefs in relation to normative social discourse this notion of subjectivity leaves no room for self-determination or self-governance.

Science, theory and practice: (see chapter 2, especially ‘subjective pragmatism and radical empiricism’). Should the evidence that guides practice be restricted to empirically demonstrable facts? Such a philosophy is called positivism, or logical empiricism. Logical empiricism attempts to identify, for example, both harms and benefits of care, and to measure them quantitatively, objectively, as if they can both, qualitatively, be valued equally as harms and benefits. This is the implicit assumption that underlies the taught and practised theory of EBM. This on the face of it has social democratic potential, a way of redistributing collective wealth and health across social classes.

However, William James’s (1842-1910) radical empiricism (1906), and pragmatism, form a scientific philosophy that values expert impressions, that is their thoughts about the effects of actions themselves, as if the thoughts of elite experts themselves are empirically observable facts that should count as evidence to guide practice.

For example, suppose an action or inquiry (into, say, the effect of screening on the problem of a particular kind of cancer death rate) yields what is, for the elite undertaking the inquiry, a desirable intended effect on the target of inquiry and action (say, a reduction in death rates for that cancer). Then their elite impression that this ‘is a good thing’ is, according to them, (because they are pragmatists), as good as an empirically observable fact and sufficient to warrant that action as a guide for future practice (say, rolling out a population-based cancer screening policy).

Note that according to pragmatism the elite are predominantly interested in solving the problem through the intended effect on the target, and are relatively uninterested in collateral, unintended, harms. And so, in the end, radical empiricism, or pragmatism, gives elite expertise the right to decide what constitutes good practice (for a critical commentary on pragmatism see Russell, 2004 p737).
Health (see chapter 1, ‘absolute normative health’, and chapter 2, especially ‘positivism and healthcare’): Is health an absolute symptom and disease free state or as Georges Canguilhem (1991) suggests a continuously evolving qualified state of being of the individual as her body autocorrects to self actualise and reset her own new norms? Using the idea of absolute health provides an impossible aspiration for care that incites limitless innovation and harm. Therefore, the concept of absolute health implies that it will be a good thing to find and identify a specific biological boundary that decides when intervention is required to strive towards absolute health. This leads to persistent and pervasive attempts to invade the healthy in search of the specifically pathological. Qualified health, as an idea, by contrast, enables us to re-imagine the individual as a delicate ecosystem that requires careful nurturing rather than an individual to be ‘maximised’ in some way.

Doing the good (see chapter 9, especially ‘the caregiving relationship and doing the good’): is it possible to know when good is being done? For pragmatism, which is consistent with the practice of EBM, the autonomous expert actor claims to know how to care and what constitutes good practice. However, as the psychoanalyst Lacan (1901-1981) says, the interpersonal relationship is always the site of an impossibility, where the other’s needs can only be imagined, and where caring carries an always present conflict between love and aggression. For population-based anticipatory care this deadlock is doubled, because the population-based care-provider has to depersonalise care, and provide care without love (Lacan, 1973 p187). The care-provider is obliged or ordered to ‘enjoy’ a normatively decided ‘good’, but at the expense of the other.

The political economy (see chapter 5, especially ‘Marx’s theory of labour power, alienation and commodity fetishism’): Is capitalism and its neoliberal variant a system that provides the best chance of a good quality life for most? Is it only natural and just that individuals should be given the maximum freedom to find work to survive, to create wealth as best they can for the best income they can make? Is it only natural and just that this leads to socio-economic inequality? My stance here is that neoliberal pragmatist ideology, as above, decides the practice of EBM, and prohibits any limits on the implementation of new forms of anticipatory care and any limits on the harm this causes.
Language (see chapter 7, especially ‘the cancer diagnosis as a product in exchange – the coercion to be a care consumer’, and chapter 4, the real cancer paradox): the issue at stake for language is important. For the praxis of EBM, language, simply speaking, is employed and understood as a tool to express self-evident meaning. Conversely, I understand language as a symbolic system of descriptors or signifiers that can have multiple meanings, and have some potential meanings that can be made unconscious, or ungraspable as meaningful by normative discourse. Analysis of language here looks for the deeper reading in order to identify those moments when particular meanings are made unconscious, (such as ‘overdiagnosis is a real harm, as in harmful’), and the consequences for conscious beliefs and hence behaviour (and the way it co-erces compliance).

For each of these six key ideas I employ theoretical resources and provide case histories. I have structured the thesis so that, in general, following an introductory chapter, theoretical resources are elaborated in one chapter and then illustrated using case histories in a following chapter. For example: the theory of, and contrast between, the political economic and scientific ideologies of neoliberal pragmatism and social democratic logical empiricism are discussed in chapter 2 and the way they deploy language is then illustrated with breast cancer screening in chapter 3, and the real cancer paradox in chapter 4. In a similar way, Marx’s analysis and the link between political economy and consciousness, and the theory of Lacan’s structures of discourse in chapters 5 and 6 are then illustrated by the ways subjectivities and consciousness may be shaped by cancer screening in chapter 7. Chapter 8 is an economic analysis of the political governance of a genetic signature to illustrate the sovereignty of neoliberal pragmatism over healthcare effectiveness. Chapter 9 and 10 introduce psychoanalytic theories of ‘doing the good’ through caring with love, and formation and its potential perversion, which are then illustrated by a case history in chapter 11.

Most central to the analysis however, is subjectivity, and the challenge to the commonly accepted motif of the ‘whole person’, free and responsible for her own future. Here subjectivity is formed socially, through desire and drive to pursue a sense of the self and her social relations. This is the lynchpin that points us towards the effects of the deadlocks described on health.
Marx’s (1867) analysis of capitalism is used to show that commodity fetishism is the fantasy that objectivises the capitalist and consumer alike, that incites, ultimately, the perversion of EBM. Alienation, in one sense is the separation that causes the drive to form subjectivity, and in another sense, is the objectivisation of the labourer by capitalism, and in a third form is the objectivisation of the capitalist by commodity fetishism. Whilst the individual does have agency to resist being captured or taken in charge by a particular social demand, she is always in flux between demands.

Lacan’s structures of discourse are used to map out the relations between the symbolic and the imaginary domains within which the individual constitutes her subjectivity. This identifies the place of the expert agencies that warrant EBM practice, the guidelines for care-providers, and the role of the imagination in establishing belief in that authority as if it is his or her own. This is then applied using a case history, to show how anticipatory care under capitalism also incites perverse forms of harmful care-provision.

The critique identifies deadlocks and raises questions that will enable care-providers and anticipated patients to re-imagine: a) their relations with symbolic institutional authority and its speech demands or discourse; and b) their relationship to care and caregiving. Should care-providers critically examine their own personal relation to the symbolic authorities that warrant forms of anticipatory care? Are care-providers aware that population-based anticipatory care may exploit their desires because it provides relief from the stresses inherent in interpersonal caregiving? Are they aware that anticipatory care guidelines depersonalise them but at the same time can incite them to fetishise this form of care and to seek sense and meaning by finding some satisfaction in maximising implementation? Are they aware that forms of anticipatory care demanded of them reduce their presence to suffering, and reduce the effectiveness of healthcare services and access for the most vulnerable? Are they aware that neoliberal pragmatism is effectively bankrupting both individuals and healthcare services?

Below I summarise each chapter:

In chapter one anticipatory healthcare and its paradoxical nature is described. This form of care is a paradox because in the name of doing good it is causing harm. This
chapter introduces some of the key ideas and sites for analysing this paradox: ‘doing the good’, overdiagnosis, politics and science, and opportunity costs. Key drivers of this form of care are identified as neoliberalism and scientific pragmatism. The idea of absolute health as total freedom from symptoms is identified as a driver of innovation that exploits individual desire.

Chapter two shows that what really decides best health care practice, actually existing EBM, has become an elitist and subjective process consistent with a philosophy of knowing called radical empiricism, rather than the ideal of EBM’s logical empiricism. This development is put in historical context as the move from a politically left leaning logical positivism designed to prevent a recurrence of European totalitarianism to a right leaning neoliberal pragmatism.

In chapter three the way neoliberal pragmatism works in practice is illustrated with the example of breast cancer screening. Elite experts warrant The UK breast cancer-screening programme as ‘a good thing’ despite its harms. This chapter shows how subjective elite neoliberal pragmatism use language to distort the graspable meaning of evidence so that anticipatory health care is being intensified regardless of its collateral harms.

In chapter four, neoliberalism is shown to deploy language in ways that shape conscious thought, beliefs and public opinion, and shows that there are important unconscious factors at play in this process. The term or name ‘real’ cancer is shown to function and shape belief discursively, through expert rhetoric or discourse, to fix empirical meaning and certainty to screen-diagnosed cancer as if a gold standard and accurate, as ‘disease’ even if it is non-harmful and to screening itself as ‘a good thing’. EBM practice discursively hypostatises and instrumentalises the concept of the diagnostic representation of the border between the normal and the pathological, which I identify as an unknowable. This is a crucial production of a fall in knowledge for EBM that has profound implications for its praxis.

In chapter five Marx’s analyses of alienation and commodity fetishism is used to illustrate that consciousness, in the form of beliefs, is shaped by the social relations of capitalism itself, and taken for granted cultural norms. I describe how, through anticipatory care, both the raw material of the body and, in an analogy with Marx’s
analysis, the consciousness of care-labour are put to work. The individual care-
labourer is shown to be both subjugated by her objectivisation to become an object of
labour, and is at the same time objectivised in the constitution of her subjectivity. This
is a process of subjectivisation that, from a Lacanian standpoint, does not include any
possibility for self-determination, but rather is a process by which subjectivity, the
always insufficient sense of self and role, is constituted only in response to, in relation
to, and by normative discourse and social relations.

In chapter six Lacan’s psychoanalytic idea about human subjectivity is introduced as
something necessarily created from an always fragmented, or insufficient self-
consciousness. Lacan’s structures of discourse are used as a theoretical resource to
show how the capitalist processes of alienation and commodity fetishism can be
compared to the formation of subjectivity and identity. Using breast screening as an
example this identifies the key elements and discourses at work.

In chapter seven Lacan’s discourse structures are used to illustrate the formation of
potential subjectivities through breast cancer screening discourse. This shows how
particular subjectivities are formed in relation to language as discourse of imagined
authority (medical expertise).

Chapter eight is a health economic analysis of a case history, based on the
marketisation and licensing of a molecular genetic signature. It shows that neoliberal
pragmatism, under the guise of a democratic logical empiricism, in practice exercises
sovereignty and, in its own terms, forbids any limits to the sacrifice of the cost
effectiveness to public health services.

In chapter nine, first, I describe Lacan’s concept of the impossibility of ‘doing the
good’ through the imagination of the real needs of the other. Psychoanalytic theory is
used to show how attempting to care with love causes psychic conflict and may lead
to burnout, depersonalisation, and a withdrawal from caring. Second, this chapter
shows that population based anticipatory care also depersonalises the care-provider, in
effect prohibiting interpersonal caring with love.

In chapter ten I show that the care provider of anticipatory care depersonalises the
potential patient. This means that the care provider is no longer inhibited from caring
at the expense of the other. This lack of inhibition from doing harm may lead to an
increased self-referentiality and destabilisation of the care provider’s subjectivity and this may lead the care-provider to seek to make and become his or her own Law-maker. This, the chapter argues, may result in a *perversion* of care and subjectivity that has another, fifth, structure of discourse, known as the capitalist discourse. This structure is described. It identifies conditions of possibility for caregiving that will exacerbate and intensify the harms of anticipatory care.

In *chapter eleven* a case history is described. This is based on a UK based breast surgeon who was imprisoned for twenty years in 2017 because of transgressive care practices that both under and over treated patients unnecessarily. The elaboration of this case using Lacan’s theory of the Oedipus complex is then used as an example of the destabilising perversion of subjectivity constantly demanded by capitalism and identifies the potential for exploitation of the desire of professional care-providers by capitalism.

Note that, in general I have used she/her/hers as the pronouns for individuals in general whether a care provider or patient, throughout the text, except where a specific individual apparently self-declares as male. This example may represent a patriarchal form of power, and of gender appropriation. For example, in chapter 3 I draw attention to the comments of an apparently self-declared male (judging by his first name and style of clothing), who is also white and a middle class professional, who is commenting on a female programme of care as if he knows how women should respond. I accept that this thesis is also an analysis and commentary by myself, a male, on a particular example of care aimed at biological females, and this may be considered a form of gender appropriation. However, as a GP I became interested in breast cancer screening because of the scale of the programme and its harms, and the extreme polarisation of the pro-screeners and sceptics, a division that starkly highlights what is at stake for much of anticipatory medicine. So I have felt it is more important to do the analysis than not. The issue of patriarchy in medicine is important and on-going and has been addressed elsewhere, for example (Dusenbery, 2017; Shahvisi, 2018), but I don’t explore this further here. As a male I don’t think it would be possible to adequately critique the oppression of women by medical gender discrimination.
In conclusion, then, population-based anticipatory diagnostic screening care is shown to exploit the desires of both care providers and care-labour whose subjectivities are constructed by and through the discourse structures of capitalism and the effects of commodity fetishism and alienation.

This form of care is necessarily anti-democratic because of the inherent knowledge imbalance between carer and the cared-for, but in addition it coerces compliance and consumption under the illusion of transparent shared decision-making and its false premise that overdiagnosis can be valued, by an individual, as a personally relevant harm.

This mode of care is also shown to be destructive in several ways. It causes opportunity costs that reduce the effectiveness of public health care services, it reduces the presence of care to symptomatic suffering, it causes individual financial toxicity, it has unknown impact on individual potential to self-actualise health, and it removes the potential for inter-personal caring with love, making it easier not to value collateral harms as harm, and inciting a perverse excess of intervention.

The actually existing practice of Evidence Based Healthcare or Medicine (EBHC, or EBM) is warranted by a subjective, elite, neoliberal pragmatism. This places in power those whose subjectivities are constituted by the normative effective truths of neoliberal capitalist pragmatism: the expert elite and politicians. This power and these truths ensure and demand that anticipatory medicine should be warranted and extended as a good thing regardless of collateral harms. At the same time political-economic neoliberal capitalism demands innovation and deregulation of the market so that harms to social justice are no longer relevant and all that matters is the continuing circulation of commodities. Anticipation, and anticipatory healthcare is shown to: a) turn future life itself into a commodity that promises the possibility of limitless surplus life (immortality), b) depersonalises, and c) incites a perversion of care where intervention, and excess intervention, is valued for its own sake.

So, what questions do these findings raise for care providers and the practice of EBM? This thesis provides a challenge, (on the basis of the exploitative and harmful consequences of this mode of care) to the dominant prevalent normative effective truth that this mode of anticipatory medicine is a good thing. The subjectivity of care-
providers can be provoked by this challenge to unform and reform their beliefs and behaviours in relation to anticipatory medicine and what makes for, and so warrants the practice of, ‘good’ care.

So, I invite care providers to question their allegiance to the institutionalised ‘law’ that states this anticipatory diagnostic mode of care is a good thing, and to consider their personal ethical response to the impacts of this mode of care on five grounds: a) visible and invisible harms; b) equitable access to affordable care; c) threats to the unknown eco-biological potential of human life to reset its own norms; d) illusions that over-value the impact of anticipatory tests; and, perhaps most importantly of all, e) the practice of inter-personal care with love for present day suffering.
The care paradox

Introduction

This chapter introduces the anticipatory healthcare paradox whereby increasing forms of care in the name of ‘doing good’ are, instead, causing increasing harm.

Two concepts, or signifiers, are introduced, overdiagnosis and ‘doing the good’, that play an important role in creating meaning and effective or normative knowledge production.

First, I describe the type of harm that in healthcare terms is known as overdiagnosis. The question is: can overdiagnosis be valued? To what extent is it ever possible for an individual to imagine, or value, her potential overdiagnosis as a personal future potential harm for her? This is important when considering claims that using ‘shared decision making’ enables fair and democratic decision-making.

Second, I describe the idea of ‘doing the good’. The question is to what extent is it ever possible to know what is actually ‘good’ for the other if the other’s actual needs, from the perspective of the other, are only known to the other and are inaccessible to the carer, no matter how well intentioned the carer may be.

I then introduce the way neoliberal capitalism puts to work the concepts of: a) health; b) science; and c) the future life of individuals. I use the term capitalism to refer, simply put, to the economic system in which labour is employed for wages to make profit (or surplus value) for the owners of the means of production of commodities exchanged in a market in a universal form of value, money, for a price governed by supply and demand. I use the term neoliberalism as applied to this economic system, as an ideology that believes that leaving the market free of political regulation is a good thing. So that, according to this neoliberal ideology there is no desire to redistribute wealth or to mitigate socioeconomic inequalities.
First, the concept of ‘absolute’ health is an aspirational but impossible ideal that provides the perfect goal for a system that relies on limitless innovation. Second, the praxis of scientific pragmatism is a way-of-knowing, to guide practice, that grants elite expertise the limitless freedom to warrant endless innovation. And, third, the contingent, precarious and actually unknown future life of individuals provides the perfect lure and object of care for the desires of both the care-provider and the anticipated patient: the labourers producing and consuming care commodities.

The regulation, appraisal and implementation of new forms of care and diagnosis

New forms of care are being generated all the time, and with increasing speed, including innovative therapeutic treatments and diagnostic technologies. Decisions have to be made about the research and development investments in new technologies, and how to market, and whether to implement, them. As the reader may imagine, this is a very complex area.

New technology is regulated, to some extent, in terms of safety and effectiveness, but under neoliberalism perhaps less so as time goes by. Neoliberalism, briefly, refers to the political-economic system of capitalism that operates according to rules that maximise the freedom of individuals to create wealth at the expense of collective well being by deregulating the market as far as possible from any central political restraints. The issue of implementation is also complex, and has market, economic, political and clinical implications.

Industry, with its academic scientific partners, aims to maximise sales in order to maximise shareholder profits and returns for investors. Industry markets its products to both individuals, and to budget-holding national governments or federal states, to ensure they become incorporated into products insured by insurance companies and into professional guidelines.

Funding of healthcare is also complex, and highly variable from country to country. Briefly, it may be funded at state level, through mandatory not for profit insurance schemes (Netherlands), by income-based insurance schemes with limited access and cover (USA), or by mandatory taxation (UK), or it may be funded privately by individuals or companies.
The provision of care may be by a mixture of state owned and private business, but is increasingly dominated by the private sector. Governments commission institutions to regulate the marketability of new technologies (such as the CDC, Centre for Diseases Control) in the USA, and the purchase of new technologies for state funded care (such as NICE, National Institute for Health and Care Excellence, in the UK).

One question faced by regulators is: what is affordable care? What care is worth spending more on, even if it means reducing spending on other forms of care?

At a political level questions of access arise: how can care be regulated so that the distribution of, and accessibility to, care is collectively just, and maintains levels of access of care for all, including for those in poverty?

And questions of ethics arise as well: is the offer of care made in ways that are validly democratic, that is, does it take into account both a) the transparency of the information available, and b) the limits to the possibility that the information can be actually valued, and taken into account by individuals when decisions about care are imposed on them?

The anticipatory care paradox

The anticipatory healthcare paradox is that all kinds of anticipatory and apparently protective forms of healthcare are being ever more intensively imposed, even whilst they cause increasing harm. In other words, the anticipatory care paradox is the contradiction by which the increasing use of anticipatory care technologies, such as implementing new definitions and diagnoses of mental ill health, or population-based screening for heart disease risk or cancer, that are aimed at preventing future disease, are instead undermining healthcare and creating more illness. Illich termed this: ‘the paradoxically counter-productive effectiveness implicit in disproportionate techniques’ (Illich, 1995 pii)

For example, a review by the Cochrane collaboration (current internationally recognised expertise in systematic reviews that combine the results of several studies) in 2013, found:

‘ … if we assume that screening reduces breast cancer mortality by 15% and that overdiagnosis and overtreatment is at 30%, it means that for every 2000
women invited for screening throughout 10 years, one will avoid dying of breast cancer and 10 healthy women, who would not have been diagnosed if there had not been screening, will be treated unnecessarily. Furthermore, more than 200 women will experience important psychological distress including anxiety and uncertainty for years because of false positive findings’ (Gøtzsche & Nielsen, 2011 p1)

In the UK context, 2 million women are screened every year, the programme estimates 1300 breast cancer deaths are prevented, and it is estimated between 4000 and 7500 women are overdiagnosed (Marmot, 2012). And, in addition, there is no evidence that breast cancer screening reduces age-specific mortality rates.¹ This may possibly be due to confounding factors such as some differences between the screened and unscreened populations but it also leaves open the possibility that screening and treatment themselves may be causing death, and this is plausible since the x-rays of mammography are known to be carcinogenic and may also cause arterial damage too (Baum, 2013). This is discussed further in chapter 3.

The paradox is also that innovative anticipatory care technologies are being encouraged politically, marketed by industry and implemented by professional caring institutions, as ‘best evidence’, despite causing demonstrable increasing harm due to, for example, adverse effects, opportunity costs and overdiagnosis.

It seems that healthcare political policy makers and professional specialist guideline producers are simply not taking the fact and scale of these harms into account in their decisions about what constitutes good care and practice.

Healthcare policy and professional guidelines are often justified by discourse of Evidence Based Medicine or Healthcare (EBM or EBHC). I will limit my reference to EBM. This is discussed in detail in chapter 2, and I explain my use of these terms here. I use the terms EBM or EBHC to refer to both theory and practice, and I differentiate between these two uses: the theory of what is called EBM, and the basis for the formal education of those who wish to practise EBM, is based on a scientific philosophy, logical empiricism, as an ideology with objective, and social democratic potential (Howick, 2011). However, the actual practice of EBM, especially in terms of what becomes ratified by professional guidelines or public health policy (such as
cancer screening), subverts this attempt at objective, logical empiricism, and, as I will show, is heavily influenced by neoliberal pragmatist political-scientific philosophy and discourse. And, as I will also show, in addition logical empiricism even provides an apparent (but illusory) basis for justifying neoliberal and pragmatic EBM practices as democratic because, for example, it assumes that shared decision-making practices enable the autonomous patient to make a free choice.

In this chapter the concepts of health and care, which are important objects of so-called EBM, are examined, and re-imagined, in order to highlight some of the less obvious adverse effects of anticipatory care and the problems it raises for carers, patients and policymakers.

**Collateral harms**

These harms are collateral because they are harms caused to individuals and not to the cancer itself, the intended target. They are also *iatrogenic*, that is, caused by healthcare as an effect of professional caring activity: iatrogenic: Greek, *iatros*, physician, *genein*, to produce.

To critique anticipatory care isn’t to claim that all forms of healthcare are unjustifiably destructive. It is helpful to consider the different types of harm and to clarify some of the terminology that is used.

It is clear that *all* modes of healthcare *always* have the capacity to cause harm. This harm takes different forms, and some are unavoidable and justifiable, and some avoidable and unjustifiable, or oppressive. Iatrogenic harm may be:

- a direct result of the treatment (for example, the loss of a breast by surgery due to symptomatic cancer),
- a predictable but not necessarily expected side effect (for example, post operative complications such as infections, chronic pain, or depression),
- a predictable and expected side effect (such as blurred vision and dry mouth with some antidepressants),
- an unpredictable side effect (such as an allergic reaction),
• a misadventure, or avoidable human error (such as harm due to administering the wrong medicine after misreading a prescription), or

• unnecessary treatment due to a wrong diagnosis (a false positive or overdiagnosis) due to an inadequate diagnostic test.

A false positive diagnosis occurs when a diagnostic test indicates disease when it can be demonstrated that there is no disease (for example, if a particular test, say a screening chest x-ray designed to detect cancer, returns a positive result but the lung biopsy then shows that it is not cancer).

And finally, there is a subtle variation on the false positive, which is overdiagnosis.

**Overdiagnosis**

Overdiagnosis occurs when the diagnosis is technically correct, for example the patient symptoms or tissue pathology appear to match the diagnostic criteria for disease, and so, to all intents and purposes, there is disease, but where, if left untreated, this *apparent* disease would not go on to cause any of the anticipated future problems or symptoms of that disease in the patient’s lifetime.

For example, overdiagnosis occurs with breast cancer screening, but although it is a known fact it is also difficult to grasp. And, this is partly because it is only known as a fact ‘indirectly’.

Consider, then, how the fact of overdiagnosis is deduced. In theory, if there were no overdiagnosis, then each early asymptomatic screen diagnosis would correspond to a later symptomatic presentation and diagnosis in a matched non-screened population. However, in practice, there is a discrepancy between the numbers in the screened and non-screened populations. In practice the numbers of early diagnoses of cancer made by screening considerably exceed the numbers of cancers actually presenting, symptomatically, over a period of time in a non-screened population. This excess represents overdiagnosis, and it is clear that ‘estimations of overdiagnosis need some indirect inference from available studies’ (Marmot, 2012 p1782) but, importantly: ‘whether a *particular* woman has had an over-diagnosed cancer cannot be judged’ (ibid. p1782 my italics).
Overdiagnosis takes two main forms:

First, overdiagnosis occurs when *technical pathological criteria* that function as thresholds for (disease free) normality (from x-rays, biopsies and so on) mislead because of a mistaken, or false prediction of future disease.

For example: a supposedly definitive cancer test such as the histology of a tissue biopsy may confirm the accepted pathological features of cancer, but sometimes such a cancer, if untreated, would never go on to harm the person in their lifetime. This may be because either, a) it would never progress (or may even regress) and so never become harmful, no matter how much time might elapse; or b) it would, in time, progress and cause harm but before that happens the person dies of some other cause.

In the case of a), there is a case for claiming the diagnosis was a false positive, because although it looked like cancer it did not behave like cancer, which suggests the definitive diagnostic criteria were inadequate, causing a mis-recognition.

In the case of b), the diagnosis is not a false positive but is valid, or a true diagnosis at the time, but one that is ultimately proved wrong, or at least ultimately irrelevant, by other future events.

Second, overdiagnosis also occurs when *symptomatic criteria* are created for a newly recognised ‘condition’, leading to diagnoses and treatments or action that cause harm.

It was Ivan Illich (1995) who most famously and potently highlighted the scale of medical, *iatrogenic* harms being caused by modern western medicine.

Illich was a radical and influential intellectual, political thinker, and educationalist, immersed within the Roman Catholic faith as a self-identified priest (even after he had been forced to officially resign his priesthood because of political criticisms of some of the policies and actions of the Catholic Church). He organised and wrote widely, particularly on education, but is now especially well known for his critique of western technological medicine, first published as: Medical Nemesis: the Expropriation of Health (shortened hereafter as Medical Nemesis) in 1975, and then a revised version, Limits to Medicine, in 1995 (Illich, 1995): ‘… a highly individuated and revolutionary critique of the personal, social and cultural influence of Western
technological medicine ... that had claimed immense cultural authority for itself’ (Di Stefano, 2017).

Illich re-published this 1975 critique, as the ‘definitive version’ with a new preface in 1995 as Limits to Medicine (Illich, 1995). The central themes of Medical Nemesis are cultural integrity and resilience, and an ‘indictment of cultural corruption’ (ibid. pvii), ‘by the paradoxically counterproductive effectiveness implicit in disproportionate techniques’ (ibid. piii) in which the ‘fundamental pathogen today is the pursuit of health as this has come to be culturally defined in late industrial society’ (ibid. pv).

Medical Nemesis critiques the way western technological medicine enables people to adapt to inherently sickening social and political realities and the way it ‘provides an assurance of personal political innocence which serves as a hygienic mask that justifies further subjection to production and consumption.’ (ibid. p169).

However, although a substantive and powerful critique, Illich’s account doesn’t attempt to provide explanatory hypotheses for why human subjectivity can be, and is being, successfully captured by the ideology of western technological medicine (a question I do attempt to address in this thesis using Lacanian psychoanalytic theory).

In the 1975 publication Illich draws attention to the way increasing ‘diagnostic imperialism’ is destroying the capacity of health in terms of a coping mechanism, and calls for a return to the art of living and suffering to be found in traditional (pre-capitalist) cultures, to place the individual within meaningful contexts from which the slings and arrows of adverse fates … suffering and death, can be negotiated (for a useful short biography and summary see Di Stefano, 2017).

However, as he says, the 1975 version was written ‘before prevention and neo-witchcraft had really taken off’, (Illich, 1995 pviii), and by 1995 he sees the ‘formation of physicians … as the subscription to a Self-Care journal that transmits system ideology’(ibid. pix) in which the ideas and terms of coping and ethics.

So, in 1995 Illich makes important two critical observations of his own 1975 publication.
First, in 1975 Illich describes health in terms of ‘… an intensity of autonomous coping ability … as a responsible performance in a social script’ (ibid. p. vii). But, by 1995 he regrets this use of the term coping to define health because, he suggests, it has enabled technology to appropriate and frame the subject as a kind of ‘black box’: which ‘dissolves the kind of flesh that could practise the … art of enjoyment … or the art of suffering, by implying individual auto-poeisis, responsibility and self-perception’ (ibid. p. viii). This, he suggests, has allowed the term ‘coping’ (in the same way perhaps as the term resilience does today) to function as a kind of signifier used by technology to subject the individual to being objectivised as a ‘system’ responsible for its own self-control.

So, by 1995 Illich insists upon making a distinction between suffering and coping: ‘As soon as you understand suffering as coping, you make the decisive step: from bearing with your flesh, you move towards managing emotions, perceptions and states of the self perceived as a system’ (ibid. p. vi).

Secondly, in the 1975 Medical Nemesis Illich ‘raised questions of ethics’ (ibid. p. viii my italics), but by 1995 he wants ‘to indict health care not as a demoralising but as a nihilistic agency’ (ibid. p. viii my italics). I suggest that his concern here is also reflected in this thesis: that population-based anticipatory diagnostic health care is not immoral as such precisely because it depersonalises. It is nihilistic or amoral because it excludes inter-personal care with love (or even hate), and makes indifferent unconditional demands for continuing production and consumption that constitutes, in its own terms (as subjects of science) the care-providers and the lay public as objectivised systems or ‘black boxes’.

Thus, Illich provides us with two cautionary lessons.

First, there are potential risks in framing health even in qualified terms as ‘coping’, as if something auto-poetic and self-regulatory that re-sets norms, (as Canguilhem (1991) does) as this may allow the subject and body to be signified by technology as a system that can be appropriated by neoliberal capitalism and used by anticipatory medical technologies for diagnosis and treatment.

Second, Illich’s emphasis on restoring the art of suffering suggests caution is needed before placing too much emphasis on ‘presence to suffering’ by care-providers.
Invoking such presence, as if desirable, may seem to presuppose a need (imagined by the carer) for such presence. But there may be no such need and although such presence may be requested by the suffering I suggest that care-providers should try to remain aware of the risk of such presence harming the sufferer’s individual capacity to practise what Illich calls the art of suffering.

Securitisation

There is also a generalised global securitisation paradox, where securitisation refers to the kind of insurance mechanisms with which the state claims it protects the multitude of people from all kinds of threats. But, where instead in reality, it is clear that these insurance mechanisms, and security measures of all kinds, are failing to protect the people and are causing increasing harms due to wars, poverty and inequality of access to healthcare. This is, in general, the securitisation paradox.

This securitisation process has been examined by a range of philosophers interested in biopolitics (including for example, Foucault (Foucault, 2004), Agamben (Agamben, 1998), Esposito (Esposito, 2008a), and Kordela (Kordela, 2013c)): the way the biological life of the citizen is ‘ordered’ socially by, and interacts with, political power and the legislations it enacts that enforce that power. There is a fault line in biopolitical theory that should be mentioned here, although I will not explore this in detail. In simple terms, there are those (such as Esposito who draws on Deleuze, see below) that believe the human life, condition, and consciousness can, and will one day, progress towards a kind of unity with the real of materiality, and, on the other hand, those who believe the human condition is, and always will be, irrevocably divided from the real of materiality.

I describe below Esposito’s well known approach to biopolitics, (which draws heavily on Foucault) in order: a) to contextualise my account and b) to identify what is at stake in this account in terms of human subjectivity, and how Esposito’s ‘affirmative’ ‘humanist’ approach is contradicted by the standpoint I take in this thesis.

This is important because it highlights that what is at stake in determining if one believes whether human biopolitics is progressing towards some kind of quasi-Hegelian, optimistic, emancipatory future (the affirmative view), or not, is whether the human subject is considered to be fully self-aware and autonomous or, as Lacan
would have it, to not be fully self-aware (and, instead, permanently divided from the self by language between a consciousness (and desire of desire) and materiality. My standpoint in this thesis takes the latter Lacanian view.

By ‘humanist’ I mean an approach that takes the human individual to be fully self-conscious. My standpoint is that the human subject is never fully self-conscious, and originally a sense of self is constituted for the individual, only in relation to speech, language and the unconscious, without any degree of self-determination, and only through a process that prohibits self-referentiality. This should become clearer below. Hence, I argue that Lacanian psychoanalytic theory of subjectivity and the idea of the unconscious are necessary to grasp biopolitics.

Esposito, for example, by way of contrast, takes a view that such securitisation is part of a progressive dialectic, that is to say, a mutually dependent site of action between a) Life’s propensity to forever exceed its boundaries, and b) the political order’s apparent need to provide a freedom from life’s self-destructive tendencies in order to maintain the social fabric (Esposito, 2008b).

Esposito attempts to explain this securitisation paradox with what he has termed the ‘immunisation paradigm’: the intensification of mechanisms to protect life that result in the increasing destruction of life (ibid.). He draws from Hobbes, Locke and Berlin’s accounts, respectively, of sovereignty, property and freedom (ibid.).

Esposito’s paradigm contains the key elements for what he terms, following Foucault, subjectivisation within capitalism, as previously described by Foucault’s concept of biopower. The paradox emerges because of this subjectivisation of the individual. This is where the state exercises power by subjugating the individual in a way that is conditioned by her ‘subjective participation in the act of domination’ (Esposito, 2008a p35). The individual’s (assumed to be full) sense of self is both conditioned as a) a state of personal identity and b) a confessionally marked responsibility to the ideology of the state. The state’s power is maintained through a governmentality that emphasises individual responsibility, but through ‘police science’ methods that are characterised by a positive ‘doing the good’, the aim of maximising the productivity of the population’s totalised life, even whilst at the expense of that life.
This pastoral power, in which ‘the sheep’ (Esposito, 2008a p35) become both individualised (as responsible) and collectivised (as non-individual), is maintained by supposing that the state is threatened by weakness within, and imparting the fear of this threat to the individual. And the state imparts fear and exercises and maintains its power by identifying ‘illness’ or ‘otherness’ as that which must be destroyed for the collective good. Nation-state power can only be maintained by continuing this (bi-racist) process which leads to the legally enforced and normative increased sacrifice of ‘life’, but life not as a citizen with status as bios, but as a human being that is marked as ‘existence without life’ (as termed under the Nazi regime during the second world war), (Esposito, 2008a p134 and p 154) or homo sacer (Agamben, 1998).

However Esposito described his biopolitical account as ‘affirmative’: as a dialectic continually progressing from its origin towards some kind of eventual unity between human consciousness and the material world, as ‘a plane of absolute immanence’, or ‘bliss’ (Esposito, 2008a p192). This affirmative account implies that the human life is already wholly fully self-conscious from its inception as an individual with an identity.

**By contrast,** the standpoint I take in this thesis radically challenges Esposito’s affirmative biopolitics and its progressive dialectic. From a Lacanian standpoint on subjectivity there is no confessional subjective participation in the domination of the individual and there is no individual agency or self-determination involved in the formation of subjectivity. Kordela (2013b) argues that Esposito has failed to see the special character of the originary formation of human subjectivity as not beginning with an originary opposition between a self-referential life and the social leading towards a dialectic but as beginning instead with an originary prohibition of self-referentiality (Kordela, 2013b). This is why Kordela argues that it is necessary to turn to psychoanalysis and to posit an unconscious and a meta-phenomenology: the effects of perceptions that are known but rendered unconscious or meaningless (Kordela, 2013a pp73-76).

The increase in insecurity in the name of increasing security is evident in domains that include: military conflict, domestic security, financial deregulation, social welfare and healthcare. It is evident, for example, in: a) increasing conflict and refugee crises due to foreign war and global ‘anti-terror’ policies (Dillon & Lobo-Guerrero, 2008;
The care paradox – chapter 1

Halper, 2015); b) increasing global poverty and social inequality (Davis, 2006); and c) increasing lack of access to healthcare and increasing harms due to overdiagnosis in the name of preventing future disease (Gilbert Welch, Schwartz, & Woloshin, 2011).

The so-called war on terror and anticipatory healthcare share a basic premise. This premise is that your bio-security, that is your life, is under increasing threat, but the nation state will protect you from these threats as long as you, the individual, continue a) to sanction and even demand ever more security for you even when it means restricting your own freedoms, and b) to actively participate in the continuous hunt for and eradication of your own hidden disease.

Absolute, normative, health

In this section I consider the concept of healthcare itself, starting with an examination of its two constituent elements: ‘health’ and ‘care’.

For professional health carers it might seem to be self-evident that health is the object of care, that is to say, that care is aimed at promoting health. But, in fact, the potential meanings of both of the terms involved are not always evident; in fact there are multiple meanings and they can contradict each other.4

Briefly, the common understanding of health is: a state of total, or absolute, ‘wellbeing’ or lack of suffering; and care is the mechanism by which it is hoped this absolute state can be achieved, or, at least aspired to5.

This idea of health, an absolute absence of symptoms, privileges the idea of perfect wellbeing as the goal, or the desired consequence, of care, rather than the amelioration of suffering.

Care without borders

Neoliberal ideology aims to deregulate the market of the capitalist economic system as far as possible, to prevent, for example, any state enforced price controls, any limits on the marketisation of products, and to maximise the freedom of business enterprises to make profits. This is the principle of what Foucault called neoliberal governmentality, or the rationale of neoliberal government and ‘American anarcho-capitalism’ (Foucault, 2004 p104). This coupled with the demand to maximise the
performance of every life has come to dominate the professional and public perception of what makes for ‘good’ care, that is, care that should be freely marketed to all.

Increasingly, the care of health is configured in accord with capitalism’s need for competition, which necessitates the relentless drive for the continual growth of healthcare enterprises through innovation in technologies of treatment, diagnosis and prediction.

The idea of health as an absolute implies that every life is not yet perfect enough and, in fact, should be improved. This demands that technology must be increasingly mobilised in the limitless pursuit of what is in fact an impossible, aspirational, concept of health.

Thus, under capitalism, healthcare products have become a growing market for anticipatory care in general, and especially for the highly technical markets for what is called Predictive, Preventive and Personalised Medicine (PPPM), or Predictive, Preventive, Personalised and Participative medicine (the 4Ps) (Jennings, Shakespeare, & Loke, 2015), described as ‘the nucleus for advanced healthcare’ (Golubnitchaja, 2017 p81).

There is now direct access for the public to blood tests for genetic signatures that indicate risks of certain diseases, or to characterise and design ‘your personal’ optimum lifestyle (kind of diet, ‘personalised sleep algorithms’, type of physical activity to maximise your sporting performance).6

Qualified health

However, as the French philosopher Georges Canguilhem put it the concept of health can also be re-imagined, as the individual’s unique ‘margin of tolerance for the environment’s inconstancies’(Canguilhem, 1991 p197), or, in other words, a measure of her potential to reset her own margin of tolerance (which becomes her new normal state of health) in response to internal or external assaults. In other words instead of health being an absolute aspirational state of being it is instead a variable functionality, that is, a qualified idea of health as the personal potential to perform to resist harm to life, or, in other words, to resist death.
Health: Canguilhem (1904 -1995), the French historian and philosopher of science, made an important distinction between ‘absolute normative health’ and ‘qualified health’:

‘… health, taken absolutely, is a normative concept defining an ideal type of organic structure and behavior; in this sense it is a pleonasm to speak of good health because health is organic well-being. Qualified health is a descriptive concept, defining an individual organism’s particular disposition and reaction with regard to possible diseases’ (Canguilhem, 1991 p137)

He described the concept of: qualified ‘ … health … in silence’, that is, the qualified health of the asymptomatic person, as good health. Thus, good health is that which is experienced, but not noticed, by an asymptomatic individual. He developed the concept, that ‘health is lived in the silence of the organs …’ first described by the French surgeon and physiologist Leriche (1879-1955) (ibid. p91). Canguilhem rejected the concept of health as an absolute, and regarded qualified health, in general, as the potential of a given individual to go beyond any given normal by creating his or her own new norms.

In disease, Canguilhem suggests, life has the potential to transcend a previous norm and to settle at a new norm, albeit with an ongoing ‘reduction in the margin of tolerance for the environment’s inconstancies’ (ibid. p199). Thus, in disease, humans are ‘… tethered to norms, often new norms’ (Introduction to Canguilhem: Writings in Medicine Geroulanos, 2012 p3).

But, ‘positivist conceptions misunderstood this, … erasing individual reactions to disease …’, and ‘ … in so doing they effaced the experience of suffering and … of health itself’ (ibid. p3 my italics). And, Canguilhem claims that ‘ … a normativity based on statistically engendered normality fails to explain the complexity of physiological disorders and the individual patient’s relation to his or her environment’ (ibid. p3).

Canguilhem critiques positivism’s conception of health: ‘We cannot fail to recognise that … an ideal of perfection soars over this attempt at a positive definition’ (Canguilhem, 1991 p57 italics in original). He radically challenges the idea that disease is abnormal, instead disease and pathology are normal and he defines health
as indicated by an individual’s potential to auto-correct, respond to, and to set new individual or personal norms.

Thus, instead of being an aspirational impossibility that drives a search for ever more health care interventions, health’s essence is the individual’s potential to tolerate and compensate, and to secure its structural and functional integrity, by facing up to, and in the face of, ongoing external or internal assaults on that integrity.

The apparently diseased and symptomatic state is still ‘a normal’ for the given individual, which ‘ … consists in being able to live only in another environment and not merely in some parts of the previous one’ (Canguilhem, 1991 p137). And so, rather than thinking of the normal as a state of some kind of perfection, the individual’s state is instead in a perpetual normal state of violation of her structural and functional bodily norms, ‘the actual notion of the normal depends upon the possibility of violating the norm’ (ibid. pp198-200). In this way, then, the symptomatic individual, ‘normative man’, transcends what was his asymptomatic, or less symptomatic, norm, to establish a new normality. The individual’s health resets and optimises his or her margin of tolerance at a new, albeit reduced, level. This is the exuberance of Life as ‘more than normal’ (Canguilhem, 1991 p91). A key point to note here is that by straining to preserve life’s present state, ‘living the withdrawn life’ (ibid. p91) the individual may reduce her potential to respond effectively to ongoing risks.

So, it is now possible to imagine that good health can be promoted in terms of enhancing the individual life’s potential to tolerate its environment. If this is imagined then the aim of care may change from, a) what was an impossible aspirational goal, that is, the maximised and symptom free life, to; b) the protection of every individual’s fragile human socio-eco-biology.

This re-imagining of the health concept may help to stimulate a shift from a harmful technocratic attempt to manipulate and maximise life’s future performance, towards a more sensitive nurturing of the individual life’s innate capacity to find its own balance. It may shift the notion of what constitutes good care towards a greater emphasis on present suffering.
Doing the good

In general, caring implies ‘doing good’ for the other. But what are the conditions of possibility that may incite and limit care for the other, without harming the other?

The taken for granted meaning of well intentioned care or ‘doing the good’ as being always beneficial and ‘a good thing’ can be critiqued because: a) care becomes impersonal when based upon average population outcomes rather than individual needs; b) the wider harms of healthcare are ignored when it is evaluated according to a limited and narrow relevance to some active intent or aim, as in pragmatism (discussed in chapter 2); and c) care can be misguided and cause harm when it is based upon the carer’s own perception of what the other’s needs must be as if they were the same as the needs the carer imagines her needs would be, rather than upon what they are actually are. But who decides what is good care practice?

Under one scientific approach, pragmatism (discussed in more detail in Chapter 2), the scientific inquiry of a mode of care determines what is good in terms of its own subjective definition of what constitutes the satisfactory and intended future effects of its mode of care regardless of collateral harms.

What is anticipatory care?

Anticipatory care consists of population-based care of asymptomatic individuals that predicts and determines future health states as pathological and harmful and also determines the action that must be taken to prevent those states.

The anticipatory mode of healthcare implies more than just prediction. Anticipation implies both knowledge of a future state, or event, and how this may be forestalled, prepared for, and taken care of in some way.

Anticipation is more than just expectation. It is purposive and includes the planning of action. Consider the anticipatory mode of healthcare applied to asymptomatic individuals in relation to future potential symptomatic illness. Anticipatory care a) predicts future disease, in advance and b) takes in hand the prevention of future disease by deciding the kind of care required.
Examples of anticipatory care include: a) lowering thresholds for treatment in existing patient populations, such as statins for heart disease (Parish, Bloom, & Godlee, 2015); b) lowering thresholds for diagnosis, investigations and referrals for disease, such as suspected cancer (Chan, 2015); c) advertising for people with symptoms, such as a cough for 3 weeks, to seek healthcare advice (Be Clear on Cancer Campaign, UK Public Health England, 2017); and d) extensions to the populations for anticipatory care, such as extending the age range for breast cancer screening programmes (AgeX Trial NHS England, 2017a).

In the domain of psychological anticipatory care, psychiatry continues to invent new forms of illness such as: hoarding disorder, disruptive mood dysregulation disorder, intermittent explosive disorder, and so on (Wakefield, 2016). This is increasing the fear of harms due to increasing overdiagnosis and overtreatment:

‘Many millions of people with normal grief, gluttony, distractibility, worries, reactions to stress, the temper tantrums of childhood, the forgetting of old age, and ‘behavioural addictions’ will soon be mislabelled as psychiatrically sick.’ (ibid. p107)

Within neuroscience, cognitive psychology and even ‘psychoanalytically inspired social theory’ (Leader, 2017) itself there is a tendency to define and identify biological vulnerabilities to future events. These vulnerabilities are defined as ‘states’ of mental health that can be observed and measured with, for example, rating scales, or even molecular signatures. They are then used as indicators of a) future mental ill health and b) specific interventions.

Darian Leader illustrates these two features in his critique of psychoanalytically inspired social theory whereby, ‘This colonization of the psyche turns symptoms into commodities’:

‘… much of the current thinking in British psychoanalysis takes mental hygiene as an explicit goal. Childhood problems, for example, are seen less as the expression of a subjective truth than as indications of risk for future social disruption. … if an infant is deemed poorly attached, the whole battery of mental health intervention is appealed to as preventive of future risks. … Rating scales and evaluative technology are showcased, and other
therapies berated for failing to attain this level of objectivity’ … The claims made by the attachment theorists also boast of another feature of the new market-led notion of therapies: the specificity of intervention. ‘The structured, manualised psychotherapy techniques of the future’, the Freud Memorial Professor Peter Fonagy writes, ‘will be designed to specifically address empirically established developmental dysfunctions’ (Fonagy, 2004). Dysfunction is made to exist independently of the person’s experience of it, a bias that merely reinforces social, non-subjective criteria of normality.’ (Leader, 2017 pp1-3)

This mode of healthcare always operates at a population level, but at the same time is directed at individuals.

Thus, over time, the focal point of the clinical gaze, that is, the carer’s perspective on health and the body has shifted. The concept of the medical gaze: the authoritative power to see within, and to express what is seen, that is, to classify, diagnose and treat, was first elaborated in Michel Foucault’s The Birth of the Clinic (Foucault, 2008). This clinical gaze has increasingly shifted away from the relief of present suffering to the improvement of future health through prediction and prevention. The focal point is now in the future.

And, ever more intensively, the terrain of the body and human behaviour is being explored, screened and scanned for visible signs of what the future holds. And these visible signs, extracted by technology, are expressed in the language of diagnoses: hypertension, hypercholesterolaemia, cardiovascular risk scores, dementia scores, depression scores, ‘real’ cancer (breast, cervical, bowel, lung, prostate), the BRAC gene (predictive of increased risk of future breast cancer), glucose intolerance, obesity, bone density, and so on. And, each diagnostic sign is associated with, or signifies, a treatment that is just ‘on offer’, but an offer that is, all the same, hard to refuse.

**Two modes of cure**

This more recently developed practice of prediction and prevention, or anticipation, may be thought of as one mode of cure. Because ‘cure’ itself now has two modes: a) the cure of present symptoms – which always carries risk of unavoidable positive
iatrogenic harm; and anticipatory care where b) the cure is signified, or decided, in advance of anticipated future symptoms or disease.

This new form of cure, that is, future cure through anticipation, produces things like ‘early diagnosis’, and ‘risk factors’. These incite fear, exploit the desire for security, and in effect make an unconditional demand of the patient. The person is now a patient whose role is, in a sense, to confess, so that she willingly seeks treatment and feels a moral duty to comply. Instead of care being merciful, care now offers a kind of redemption.

Anticipatory care, then, as a concept, extends the idea of just prevention to emphasise the way it actively generates increasing numbers of people that are apparently in need of treatment. It is a process that positively produces proliferating innovative categories of illness, or threat of illness, of risk stratifications that anticipate future symptoms or the potential to improve life performance in some way, and that incites the need for care and the demand for treatment.

Presence to suffering

One of the wider consequences of the increase in anticipatory care provision in Western societies is that there is less money and resources available to spend on symptomatic care. This is a loss of opportunity to spend on symptomatic care and is called an opportunity cost. The significance of this ‘cost’ idea is very important and explored more fully later but here I want to point out that this means that the focus of healthcare has shifted towards anticipation and away from present suffering. This, in turn, means that carers can no longer be as ‘present to suffering’ as they once were, a presence so well illustrated by John Berger’s classic real life account of the life, challenges, values and sacrifice of a UK country General Practitioner in the 1960s, in ‘A Fortunate Man’ (Berger, 1967).

My argument is that anticipatory care under neoliberalism is anti-democratic, it: exploits desire, coerces compliance, causes distress, bankrupts, and destroys health and care for many.

So, should professional caregivers have a role to protect lay people from having their desires exploited?
Notes

1 An age-specific all-cause mortality rate is a mortality rate for all causes of death limited to a particular age group, in which the numerator is the number of deaths in that age group, and the denominator the number of persons in that age group in the population.

2 The multitude, as used here, is the idea of a population that has not entered into a ‘just’ social contract with a sovereign political body such that individuals retain the capacity for political self-determination. The (utopian) ideal of a ‘just’ social contract, was developed by Rawls in ‘A Theory of Justice’ (Rawls, 1971) and, according to Rawls, would be one in which every individual has an equal opportunity to fulfil potential and survive according to rules that are impartial and do not favour any particular type of individual.

3 Today, politicians often justify military interventions on humanitarian grounds as, for example, in the so-called ‘war on terror’ waged in Afghanistan after 9/11, where:

   ‘The most acute oxymoron of humanitarian bombardment lies rather in the superimposition that is manifested in it between the declared intention to defend life and to produce actual death. The wars of the twentieth century have made us accustomed to the reversal of the proportion between military deaths (which was largely the case before) and civilian victims (which today are far superior to the former)’ (Esposito, 2008b Introduction).

4 The fact that some terms can have more than one meaning is an opportunity to briefly illustrate, and explain the importance of, the indeterminacy of language. This indeterminacy refers to the way that the meanings of signifiers, such as ‘health’ and ‘care’, are not fixed within a given language system but have meaning values that vary according to the symbolic order (how the chain of signifiers in language is used to decide social norms) that, crucially governs what an individual is supposed to believe and how to behave as a normatively ‘good’ citizen.

5 In fact the World Health Organisation goes further and defines health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (World Health Organisation, 1948) – a definition which makes its impossibility as an aspiration even more striking.

6 For example, the field of practice known as ‘Body Culture and Sports Medicine (BCSP)’, as promoted by adherents of so-called anticipatory medicine (for example see Nadin, 2017), markets a wide range of biometrics promised to enhance future sporting performance. This is one way in which anticipatory technologies are increasingly invading the terrain of the everyday life world.

8 Eco-biology is the study of the relation between biology and the environment. Here I use the term ‘eco-biology’ to refer to the individual’s life in terms of its potential and performance as dependent upon the combination of a) the individual’s bodily biology and its own tendency to error and relations to exogenous and inbuilt threats to integrity and function and b) this biology’s relation to its habitat (eco) through things like beliefs, personal
temperament, lifestyle, external conditions and so on. I have added socio- to capture the fact that social relations and norms have an effect on individual beliefs, and therefore behaviours, in response to the environment.

For the American philosopher CL Lewis who analysed the relations between logical positivism and pragmatism:

‘... pragmatism would regard meaning as limited ... ’, on the other hand, ‘ ... the pragmatic emphasis upon relevance to some active intent is largely or wholly omitted in logical positivism ...’ (Lewis, 1941 p94 my italics)

In other words, for pragmatism the desired intended effect on the target of the action is what has valued meaning in terms of guiding future practice, privileges, and at the same time relatively undervalues, and deprives of meaning any (non-target) collateral damage that may result from the action. By contrast the kind of science called logical positivism, (also known as logical empiricism), as the basis for knowing how to guide future practice, which is the apparent theoretical basis for the practice of Evidence Based Medicine (EBM) ostensibly claims to value both benefits and harms with equal concern. This important difference is explored more fully in chapter 2.

‘Doing the good’ is a complex idea because it conflates ethics (used here in the sense of the management of one’s individual life) with morality (considered in terms of deciding what is good for others). This is discussed further in chapter 9. There is also a good discussion of this in Parker’s ‘Psychology After the Unconscious’ in which ‘standard mainstream ethical responses to illness’ are thrown ‘into question’ (Parker, 2015b pp12-13). Three ethical approaches are all a problem because of ‘who decides?’ these are: ‘the good’, ‘duty’ and ‘the efficient distribution of good’. Simply put, according to Lacan, in seminar VII, ethics is about deciding upon a course of action to follow in the individual life, whereas morality implies knowing what is best for others. ‘Doing the Good’ may cause harm to others if it involves imagining what is good for the other according to the do-gooders personal beliefs, which may run contrary to the beliefs and wishes of the other.

The ethical position, then, for Lacan, is to resist imagining that the other’s needs are the same as the needs that you, as carer, think your needs would be in the other’s position. This may involve not-knowing, as a path for limiting harm that may be caused by a mistaken imagining (a misrecognition) of need, as well as being potentially relatively more emancipating for the cared other. If we put the professional (health) carer in the position of the psychoanalyst, then according to Lacan, we would have: ‘the psychoanalytic (carer’s) ethic rejects all ideals, including ideals of ‘happiness’ and ‘health’ ... the desire of the analyst (carer) cannot be the desire to ‘do good’ or ‘to cure’” (Lacan, 1973 pp218-219).

This means, for example, that inquiries into screening demonstrate outcomes such as a reduction in breast cancer deaths, the intended effect, as ‘satisfactory, despite collateral harms such as wrong or false positive diagnosis of cancer and other side effects. This is an outcome that is subjectively named, and normatively deemed, ‘satisfactory’ by industry and cancer specialists. These expert impressions are then deemed sufficient ‘grounds for belief’ to guide future practice, and warrant the assertion that screening is a good thing, regardless
of the scale of collateral harms it may cause. This is the pragmatist definition of a good thing and is a self-fulfilling prophecy that provides a limitless breeding ground for profitable innovative health care technologies. Bertrand Russell analyses Dewey’s philosophy of pragmatism that inserts the inquiry at the centre of human philosophical endeavour rather than a search for truth.

‘In all this I feel a grave danger, the danger of what might be called cosmic impiety. The concept of ‘truth’ as something dependent upon facts largely outside of human control has been one of the ways in which philosophy hitherto has inculcated the necessary element of humility. When this check upon pride is removed, a further step is taken along the road towards a certain kind of madness – the intoxication of power ... I am persuaded that this intoxication is the greatest danger of our time, and that any philosophy, which, however unintentionally, contributes to it, is increasing the danger of vast social disaster’ (on Dewey, Russell, 2004 p737)

These comments by Russell prefigure the discussions later in the thesis, especially in chapter 11, of the way capitalism, and anticipatory technologies, incite perversion, understood as a particular Lacanian psychic trait, or perhaps, structure. Therefore it is suggested that pragmatism’s radical empiricism, which privileges elite opinion, is a third factor inciting perversion, alongside capitalism and anticipation and ‘increasing the danger of vast social disaster’.

12 Examples of this kind of healthcare include, for example, screening for predictive risk scores for heart disease and preventive treatment with Statins to reduce risk of heart disease, screening with a variety of technologies for early breast, bowel, and cervical cancers (Parish et al., 2015) screening older people for fragility fracture risk with dual-energy X-ray absorptiometry (DXA) scan to measure bone mineral density (BMD) (Anxiety and Depression Association of America, 2017), and the use of Biphosphonates to reduce the risk of fractures in older people, and in the field of mental health, for example, screening for social anxiety disorder (National Institute for Health and Care Excellence, 2016) (UK NHS England, 2017b) and early dementia (Yokomizo, 2014), and, in the UK, the screening and treatment of the unemployed with cognitive behavioural therapy for negative attitudes to work (Gayle, 2015).
Science and politics

Introduction

This chapter introduces radical empiricism and pragmatism as the scientific basis for real-life decisions about healthcare policy. Their use explains the paradox by which destructive forms of care are commissioned even whilst their harmful consequences are acknowledged but are, nonetheless, treated as irrelevant.

In this chapter, I first describe the basis for the method that is accepted and taught as the apparent, but as I will show, in fact, illusory, basis for deciding ‘best’ healthcare practice. This is known as logical empiricism and is the basis of Evidence Based Medicine (EBM), or Healthcare (EBHC).

Then, second, I show that what really decides best healthcare practice is not the logical empiricism of EBM, but, instead, is an elitist process consistent with a philosophy of knowing called radical empiricism.

The changing role of scientific empiricism, or positivism, is described within the political-economic context of the twentieth century.

Evidence Based Medicine

So-called EBM was initiated with a ‘rhetorical flourish’ as a ‘new paradigm’ in the 1980s (Howick, 2011), largely under the influence of Sackett and others at McMaster University, Ontario (Sackett, 2003). This EBM is both a practice and a method for deciding best practice, and it is based on the development of a rational or logical empiricism (or positivism) for evaluating the effectiveness of treatments.

This method is empirical, and positivist, and embraces the population-based randomised controlled trial as the method of choice for deciding what is ‘good’ care (Howick, 2011). The outcomes of such trials are statistical probabilities of harm and benefit. And these risk statistics are then applied to individuals when making
decisions about what constitutes good care and, for the individual, the apparently ‘right’ decision.

There are two definitions for EBM worth considering. The first is the ‘official version’ sanctioned by EBM’s ‘intellectual community’ (Howick, 2011) and the second is Greenhalgh’s version (Greenhalgh, Howick, & Maskrey, 2014), which deconstructs and critiques the first definition. Greenhalgh describes this definition as ‘a skilful rhetorical move to position this new paradigm squarely on the moral high ground’.

First definition:

‘Evidence Based Medicine is the integration of best research evidence with clinical expertise and patient values. By best research evidence we mean clinically relevant research, often from the basic sciences of medicine (‘mechanistic reasoning’) but especially from patient centred clinical research into the accuracy and precision of diagnostic tests, (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative and preventative regimens … By clinical expertise we mean the ability to use our clinical skills and past experience to rapidly identify each patient’s unique health state and diagnosis, their individual risks and benefits of potential interventions and their personal values and expectations. By patient values we mean the unique preferences concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient.’ (Howick, 2011)

And, a second definition:

‘The use of mathematical estimates of the chance of benefit and the risk of harm, derived from high quality research on population samples, to inform clinical decision-making.’ (Greenhalgh, 2011)

So, the effectiveness of therapies is evaluated through experimental studies that: are population-based, use observable measurable outcomes, and produce measures of benefit or harm in terms of statistical probability, or chance.
But EBM’s definition, as a basis for its methods of appraisal of evidence and healthcare practice, has been criticised (Greenhalgh, 2011; Greenhalgh et al., 2014; Holmes, Murray, Perron, & Rail, 2006). The applicability, reliability, and neutrality of EBM’s ‘best evidence’ is in doubt because, for example: a) it is reductive (fails to take account of individual differences) (Greenhalgh et al., 2014); b) it is coercive since it incites fear and limits available options (Jørgensen, 2016); and c) of biases due to professional and economic conflicts of interest, where, for example, pharmaceutical companies have preferentially published trials that show their treatments in a favourable light (Gøtzsche, 2013).

Logical empiricism (or logical positivism)

EBM’s logical empiricism, or logical positivism, is a particular way-of-knowing that decides what can be claimed to be true, or, in terms of medical therapies, what can be claimed to work, or be effective.¹

Logical positivism, according to one of the most influential positivists, Carnap is a doctrine in which "every term of the whole language of science is reducible to what we may call sense-data terms or perception terms" (Carnap, 1964 p12). The philosophy of positivism was, in part, developed as an antidote to what was regarded as the excessive mysticism of Kantian philosophy based on the assumption that there is always an inaccessible ‘beyond’, the noumenal beyond the phenomenal.

Thus, Rudolf Carnap, of the Vienna Circle, was responding to neo-Kantian controversies.

Briefly, the Vienna circle was a group of philosophers and scientists who met in Austria between 1924 and 1936, using the philosophy of logical positivism (or empiricism) to make philosophy scientific with the use of logic. They were attempting to ‘scientise the study of society’, to improve the world through evidence-based policy. It has had immense influence on the philosophy of science and analytic philosophy that still dominates EBM theory today.

Kant (1724 -1804) had distinguished between the (a posteriori) a) sense-perceived and (a priori) b) human ‘mental’ constructs such as space and time. Kant postulated an intermediate epistemic mechanism that enables us to make 'knowledge' out of these
two things. But other philosophers, in a neo-Kantian debate, disputed the necessity for such an intermediate mechanism posited by Kant. Carnap denied any need for any intermediate epistemic mechanism and thought that knowledge should only be based on an 'accepted' use of language, and was quite happy for empiricist nominalists to use abstractions as long as they didn't believe these represented anything in the thing world. ‘To accept the thing world means nothing more than to accept a certain form of language, in other words, to accept rules for forming statements and for testing accepting or rejecting them’ (Carnap, 1936 pp463-464).

Carnap specified that knowledge should be 'based on language' which presupposes that language itself can provide or determine all knowledge that can be known as meaningful in the sense that it should guide beliefs and practice, i.e. language as having determinate meaning. But he defined in what way language can be meaningful as well: ‘Thus it is clear that the acceptance of a linguistic framework must not be regarded as implying a metaphysical doctrine concerning the reality of the entities in question’(Carnap, 1964 p3). Positivism has had profound ideological consequences as a philosophy of knowing that has come to dominate the theory if not the praxis of EBM. It means that the evidence generated, ostensibly to inform practice, is dominated by what can be sense-perceived as a result of experiment, as physically demonstrable and devalues any consideration of, for example, the way capitalism shapes consciousness through alienation and fetishism as described in the next chapter. This particular ideology is not accepted as an ideology by its proponents, that is, as something that shapes politically normative beliefs, but identifying positivism as an ideology provides insight into just how important positivism is to the theory of EBM and the way it determines how evidence is both, a) generated and b) determines how language ensures such evidence is 'accepted' or at least put to work.

Carnap disagreed with Wittgenstein about the nature of logical syntax, for Wittgenstein this was only ever a display of something of what there is out there, for Carnap this is all there is, any other questions are meaningless.

‘… the (Vienna) Circle rejected both the thesis of the reality of the external world and the thesis of its irreality as pseudo-statements’ (ibid. p8)
Carnap de-values metaphysics as a way of knowing anything, but he argued that language itself as a means of communicating sense-data is the means by which things are known. Carnap’s essay ‘Empiricism, Semanticism and Ontology (Carnap, 1964) is an important foundation for logical positivism and therefore important for EBM’s positivist philosophy (Howick, 2011).

‘Accordingly, the mathematician is said to speak not about numbers, functions and infinite classes but merely about meaningless symbols and formulas manipulated according to given formal rules. In physics it is more difficult to shun the suspected entities because the language of physics serves for the communication of reports and predictions and hence cannot be taken as a mere calculus. A physicist who is suspicious of abstract entities may perhaps try to declare a certain part of the language of physics as uninterpreted and uninterpretable, that part which refers to real numbers as space-time coordinates or as values of physical magnitudes, to functions, limits, etc. More probably he will just speak about all these things like anybody else but with an uneasy conscience, like a man who in his everyday life does with qualms many things which are not in accord with the high moral principles he professes on Sundays.’ (Carnap, 1964 p12 my italics)

What does the term ‘normality’ mean for a positivist EBM?

Here I briefly discuss the possible implications of Carnap’s for EBM and its approach to the idea of the normal. The signifier ‘normal’ as applied to health was considered in chapter 1. Here I am using ‘normal’ in the sense of an aspirational state of total freedom from disease, this is discussed in more detail later in this chapter.

Could we substitute ‘medicine’ for ‘physics’ in the above quotation, and are the limits of qualitative indications for physical magnitudes, such as the degree of abnormality of a tissue appearance, uninterpretable for the empiricist? Is an abstraction communicated in a pathology report only (e.g. say the term ‘mild atypia’ applied to a tissue sample appearance under a microscope), on positivism’s own terms, a meaningless abstraction? It may be that normality itself is an abstract term, and does not exist in fact. If so, then this suggests that an empiricist evaluative inquiry to detect spatio-temporal facts or events that rely upon an opposition to the non-existent normal must be flawed. In positivism’s terms then, EBM is faced with a deadlock
because the impossible question positivist EBM attempts to answer is not: “Is that tissue inflamed?” but is “Is that tissue normal?”

Carnap’s empiricism ignores the way language functions to disperse power through the construction of the objects of which it speaks (Foucault, 1979). It also seems to ignore the contradictions and paradoxes that occur within the thing language, whereby, for example, several different names are given to (and function in respect of) a particular borderline ‘cancerous’ (to use a name, or metaplastic, atypia etc.) tissue appearance. Similarly a physical quantity could be given different names in physics. A proportion such as 30 percent more male than female or 70 percent less female than male, can have very different social meanings. You don’t have to believe in the thing world to feel differentially subordinated by the differentiating powers of different terms and contexts.

For Carnap, language’s usefulness becomes its practical, or pragmatic, potential to guide future action:

‘An alleged statement of the reality of the system of entities is a pseudo-statement without cognitive content. To be sure, we have to face at this point an important question; but it is a practical, not a theoretical question; it is the question of whether or not to accept the new linguistic forms. The acceptance cannot be judged as being either true or false because it is not an assertion. It can only be judged as being more or less expedient, fruitful, conducive to the aim for which the language is intended. Judgments of this kind supply the motivation for the decision of accepting or rejecting the kind of entities.’ (Carnap, 1964 p7)

Here, we have language becoming a tool for pragmatism. It is to be used with ‘active’ intent, to solve a problem (the ‘aim’). This begs the question, not of the belief in the eternal thing world, realism, but of the tacit acceptance that decisions about whether to accept the naming of things may depend upon egoist interests in (economic perhaps) interest and therefore become political, a tool of a particular governmentality and market. The speaker uses the new entities, the pure empiricist may take a higher ground and argue this in no way implies belief in the reality of the new entity, but the market will sell the new entity as if it is real, and consumers will demand it with their
own mentalities shaped by the market’s use of language. This is where ‘evidence’ functions as an ideological tool that shapes consciousness as I describe in chapter 5.

To deconstruct the power effects of the language of EBM is not necessarily to hold a belief in the thing world, but is based upon acceptance of language effects of power-resistance and motivation, egoist and collective interests, agendas and non-agendas, and therefore subordination and exploitation. For example, the acceptance of the abstract entity for describing tissue in qualitative terms as ‘borderline pathology’ implies acceptance for the abstract entity ‘normality’ and does not imply a belief that ‘normality’ exists in reality, but, instead, it signifies a decision as to its (motivated) utility for the speaker. The motivation is to decide on the utility of treatment as a means of achieving normality. The acceptance of the idea of normality, as disease or error free, opens the door to infinite overdiagnosis and hinders restraint of overdiagnosis.

EBM’s methodology for producing best evidence (Howick, 2011) is an experimental and empirical positivism. ‘Positivism’ means that it relies upon the experienced, clearly seen, observable, finite, and measurable. Positivist data is ‘that which is immediately given in consciousness, e.g., sense-data, immediately past experiences, etc.’ (Carnap, 1964 p11). Under positivism, practice should only be guided by such positivist best evidence; this is because only such data is real and can be the useful knowledge that should guide practice (Howick, 2011). This means that EBM’s logical empiricism does not value some harms effectively because they are not positivist, which introduces a bias in favour of interventions.

For example, simply put, by being positivist, EBM may calculate and know, but does not actually value, as harm, abstract harms such as overtreatment due to overdiagnosis. Overdiagnosis is a phenomenon that can only be demonstrated by calculation as a population effect, and so is an abstract harm that is never directly observed, or personally experienced as sense-data.²

**Positivism and healthcare**

The origins of positivism can be traced back to the French sociologist Auguste Comte (1798–1857) (Hacking, 1990b).³ Comte’s ‘scientific method’ became the foundation
for studying individual and group behaviour and led to sociological disciplines such as criminology and psychology in which quantitative measurement is privileged.

The earliest application of positivist methods using statistics appeared in France in the 1800s with population-based studies of crime and suicide. At this time, the link is evident between this ‘science’, of so-called ‘moral analysis’, and politics. Thus: ‘In stating rigorously the numerical facts bearing on society, moral analysis forms the experimental basis of the philosophy of legislation’ (Guerry, 1829, ‘Statistique morale de l’Angleterre comparée’, xlv, cited in Hacking, 1990b p78)

Comte’s ‘revolutionary positivism’, and the concept of deviant delinquency, was inspired by a particular notion of the nature of disease and ‘the normal’ that had been developed in the mid-nineteenth century by a French surgeon and physiologist named Broussais (1772–1838) (Hacking, 1990a). Broussais had already formalised the principle that a diseased state is nothing other than ‘a normal excitation that has been transformed by an excess’, ill-health is caused by ‘…irritation and inflammation of the tissues …’ (Broussais, 1881 pp164-8; Hacking, 1990a).

The principle of disease, or pathology, as deviation is important because, from now on, it is always characterised with implicit reference to the ground of an imaginary, and perfect, ‘normal’.

Then, in the 1850s Broussais’ principle was ‘given a twist’, and ‘made powerful’ by Comte (Hacking, 1990a p168), leading to the scientific philosophy known as logical empiricism and its experienced, finite and positivist object as the basis for a way-of-knowing.

Today, the diagnostic health and life sciences use positivist methods to evaluate diagnostic processes, and aspire to identify the ‘threshold’ that disease ‘marks among natural beings’ (Foucault, 1985 pp465-477). This creates population-based normal ranges and thresholds for normality.

I want to emphasise here how this idea of an aspirational normal assumes a capacity to identify a threshold between the normal and the abnormal, which is the ‘unstated value assertion’ implied by diagnosis, leading, ultimately to a limitless proliferation of
anticipatory technologies. This is the particular unstated ‘value assertion’ of anticipatory care that remains hidden from view (Foucault, 1985 p468).

This value assertion is one reason why the ongoing proliferation of disease and risk species and their associated proliferating forms of anticipatory care, becomes the means of production of market commodities that end up prioritising the maximisation of future potential life over attention to present day suffering.

Foucault shows how the life sciences are a special paradoxical case compared to the exact, mathematical, formalised physicochemical sciences. He traces the distinctive nature of the life sciences historically: "At the end of the eighteenth century, it was thought that one could find the common element between a physiology studying the phenomena of life and a pathology devoted to the analysis of diseases and that this element would enable one to consider the normal processes and the disease process as a unit" (Foucault, 1985 p473), this, then, '... seemed to promise the unity of a physiopathology and access to an understanding of disease based on an analysis of normal processes". However, an essential characteristic of life is '... the possibility of disease, monstrosity, anomaly, and error" (ibid. p473). As a consequence "... the elucidation of mechanisms ... could only unfold to the extent that the specificity of disease and the threshold it marks among natural beings is constantly revisited" (ibid. p473).

Thus, the life and health sciences, whilst attempting to specify its object exactly, have to take into account these anomalies and errors simply because they are an essential feature of life. But, this essential phenomenon of life as error, or as a kind of mystical vitalism, whilst not necessarily 'true', and 'not constituting any unsurpassable philosophy of biologists', does have 'an essential role for us, as critical inquirers, as an indicator' (ibid. p474) of limits to life sciences, and healthcare practice.

In other words, a) there is no finite determinate threshold between the normal and diseased states, (where here, by disease I mean tissues/processes that is causing, or will cause, symptoms); b) disease becomes a limitlessly expandable and productive category for the market, science, and health care, c) the question of normality is problematic because it is always defined in terms of what is abnormal, and yet there is no specifiable threshold for abnormality. For example a blood pressure reading may,
on average for a population, indicate an increased risk of cardiovascular mortality, but may, at an individual level, possibly be an auto-corrective, healthy, protective physiological response to changing environmental or internal circumstances such as degenerative ageing. For example, a raised blood pressure may maintain the integrity of the circulation to the retina (or kidneys) and therefore of eyesight (or renal function) in response to a failing heart or narrowing arteries. This indicates to us, following Foucault, conditions of impossibility for healthcare policy based on specific population-based outcomes studies. In particular it indicates, at least, the need for caution before trusting and implementing anticipatory care of the asymptomatic through such interventions as cancer screening or cardiovascular risk stratification.

A psychological example of the mis-recognition of disease is provided by professional carer burnout for an individual who aspires to provide loving interpersonal care (Vanheule, 2001). Here, the psychiatric diagnosis of depression and subsequent treatment with anti-depressants may inhibit recourse to, and management of, the primary cause of the depersonalisation and emotional exhaustion. In this case burnout may be a protective response to a work situation where organisational demands are incompatible with providing loving interpersonal care. Diagnosing burnout as depression and treating with CBT, or medication, to encourage a return to the work situation does not address the harmful nature of the organisation’s (symbolic) demands. This may lead to a further lowering of self-esteem and a worsening of mood.

In chapter 9 burnout is described using psychoanalytic theory which suggests that:

‘Intervention should focus on the symbolic roots upon which the imaginary caregiving relation is based (i.e. the caregiver’s own oedipal history) and on the real impotence in relation to which it functions as a defence’ (Vanheule, 2002 p5)

'Disease, … and error' are phenomena of life, and indicate for us: '... the reductions to be avoided ... all those which tend to conceal the fact that the sciences of life cannot do without a certain value assertion that emphasises conservation, regulation, adaptation, reproduction, and so on’ … ‘an exigency rather than a method …’ (Foucault, 1985 p474). That is to say, science and healthcare covertly asserts values
for its diagnoses, the potential to specify normality, driven by a need to specify and improve life with its ‘facts’.

In general, diagnostic tests have a normal range, which means, usually, that there is no gold standard against which the accuracy of a diagnostic test can be measured in terms of a binary right or wrong. This, in turn, means that the use of such tests always involves a compromise in which the inevitability of the wrongly and overdiagnosed is accepted as a so-called necessary sacrifice in order to make some correct diagnoses (Newman & Kohn, 2009).

**Healthcare and social norms**

Healthcare is political and economic in three ways: a) it is *a social arena* in which political and economic ideologies compete to harness care to their own ends to obtain power; b) it is *a practice* of scientific diagnosis and treatment, that decides social norms for behaviour and practice, in ways that match political ideologies; and c) it is a *policing function*, that regulates, monitors and ensures carer and ‘patient’ compliance with these expected practices and ‘normal’ behaviours.

Foucault describes how medical institutions, since the earliest days of positivism and Comte, have policed nearly all areas of life, to regulate institutional practices, personal behaviour and social relations (Foucault, 1979, 2008). These behaviours have, for example, included madness, sexuality and addiction. Within psychology and psychiatric institutions this regulatory function is shown in: a) the continuing extension of diagnostic categories by the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Wakefield, 2016); and b) the use of psychological therapies, through CBT (cognitive behavioural therapy) (Gayle, 2015), and addiction treatment regimes (Holehouse, 2014) to police the social benefits system for the unemployed and people addicted to drugs.4

Cancer provides a good example of the way politicised science and care practices interact. Care such as cancer prevention and cure forms a part of nationalist propaganda. National governments cite cancer care, through cure or early diagnosis, as a way of demanding more care to keep up with the diagnosis or cure rates of other countries.
Thus, cancer is a vehicle for economic and political interests. For example, the National Socialism of Germany in the 1930s invested heavily in anti-cancer research and propaganda (Proctor, 1999), and Obama, the ex-USA president, more recently called for a cancer cure ‘moonshot’ in his state of the nation address, pledging extra funding (McCarthy, 2016).

This raises a question: what is at stake for politics? At stake for politics, under advanced capitalism, simply put, is: a) the individual freedom to act for the self (neoliberalism); versus b) the promotion and protection of collective wellbeing (social democracy). At this point I will describe the two dominant ideas, or ideologies, competing for political power under capitalism today. Here are the key terms I will be using:

Social Democracy: I am using this term to describe a form of welfarism, a general aim that is still liberal, that is, promotes freedom of the individual, as well as capitalist, that is, promotes the freedom of capitalists to employ labour to make profits, but promotes a political system that is concerned for the distribution of welfare across all the people, and tries to put in place mechanisms that regulates the market so that prosperity, and healthcare, are distributed fairly across society.

Neoliberalism in healthcare promotes liberalism via the structures that maximise the freedom of any individual specialist interest: a) to dictate regulation to the state; b) to compete with the interests of other specialities; c) to aggressively market its own product, or fail; and d) to be free of market regulation by the state. It encourages and rewards the personal, an individualism that focuses on only the interests of ‘your’ particular enterprise, as if in deadly competition with others.

Science and politics: a turn from the left to the right

There is also a relationship between science in general, and politics. To remind the reader, the anticipatory care paradox is where increasing numbers of anticipatory forms of care, such as cancer screening, are being imposed, despite the evidence that this is causing increasing collateral harms, such as overdiagnosis.

The attempt to disentangle the deeply interwoven relationship between science in general, and politics, helps to reveal, in part, the underlying mechanisms of the
paradox. And, the historical political context for the ascendancy of positivism in science in the West in the twentieth century provides insights into the forces at work that sustain and intensify that relationship.

Logical empiricism, or logical positivism, was described earlier in this chapter. It became the dominant Western philosophy of science that also emerged, in part, as a force for the political left in Europe through the 1920s and 40s. Briefly, as a philosophy, logical empiricism only values as meaningful, that is, as that which should guide practice, those facts based on: a) experience, that is that are observable and measurable; and are, b) proven through use, or experiment.

The ‘left’ here is used as a loose term to indicate a political ideology that resists inequality, elitism, national imperialism and the exploitation of labour, and that argues for a redistribution of opportunity and wealth to maximise self-determination.

The twentieth century saw world wars, economic turmoil, and political upheavals. Creath suggests that, in the 1940s, the ‘main leaders of the [logical empiricism] movement’ were responding to levels of ‘political convulsion that had not been seen since the French revolution’, and ‘were politically and culturally engaged’ (Creath, 2017). And, ‘this … was accompanied by the conviction that their cultures were incapable of the necessary reform and renewal because people were in effect enslaved by unscientific, metaphysical ways of thinking’ such as ‘the racial hatreds of the day’. It was, Creath suggests, ‘a political act as well … to strike a blow for the liberation of the mind’ (ibid.).

Simply put, it was hoped that, by using scientific inquiry to evaluate social impacts of new technologies, logical empiricism would provide a more democratic basis for social development, and would avoid the dangers associated with the abstract ideologies, such as Nazism and Stalinism, that promote apartheid, prejudice and inequality.

But then, in the 1950s, came a turn to the political right.

The horrors of Stalinist-style state ownership and control in the USSR was used, as an example, to condemn Marx’s theories and socialism as a force for evil.
The Stalinist terror was the result of a particularly destructive state-based form of capitalism, and was a corruption of Marx’s ideas and socialist ideals. However, the Stalinist reign of terror did emerge out of the 1917 ‘communist’ revolution, and so the Soviet experiment came to be used as a powerful propaganda tool for the anti-communist liberalism of the right.

After the Second World War there had been attempts at social democracy in both the UK and America, in the form of programmes to guarantee security ‘of employment, with regard to illness and other kinds of risk, and at the level of retirement’ (Foucault, 2004 p216), but these were gradually eroded by neoliberal forces.⁸

Neoliberalism, of the American kind, Foucault suggests, is ‘a whole way of being and thinking’ (ibid. p218), where ‘liberalism is at the heart of all political debate’, and ‘the founding and legitimising principle of the state’ (ibid. p217).⁹ And, today, neoliberalism’s demand for increasing productivity defeats social democracy’s demand for collective welfare.

The ability for neoliberal capitalism to correct for the falling rate of profit anticipated by a Marxist analysis, is attributed to not only imperialist activities and the invasion of other nations for their resources (Luxemburg, 1951), but also to ‘innovation … the discovery of new techniques, sources and forms of productivity, and also the discovery of new markets or new sources of manpower’ (Schumpeter, 1943 pp139-42). The important point here is that the increase in productivity is not only achieved by investing in human capital but also through the continuing introduction of innovative technologies, that is, by making human capital more productive as well (Foucault, 2004 p231).

It is no coincidence that the logical empiricism of EBM also emerged in the 1980s and functioned as the ideal tool to generate evidence of the effectiveness of innovative technologies. And, at the same time, the ‘pervasive problematic’ of overdiagnosis due to anticipatory care is a manifestation of the demand for more productivity out of human capital, as clinical labour.

Thus, the logical empiricism of post-war Europe, was, apparently, developed ‘to strike a blow for the liberation of the mind’ from nationalist ideologies. It became, by
the 1980s, the dominant method for assessing the effectiveness of innovative health technologies.

In the 1980s, the UK’s Thatcher government approved the introduction of the population-based breast cancer screening programme despite its unevaluated collateral harms (Forrest, 1986).

This approval, of action to innovate and intervene, is consistent with a philosophy in which the thoughts themselves, that is, the subjective views of the elite experts appointed by the neoliberal state, are regarded as a form of empirical output and therefore necessarily a form of truth and of social progress – this is radical empiricism. And, in addition, this approval of the action, to innovate, is consistent with pragmatism in which only the effects on the intended target are considered (breast cancer death reduction) and not the collateral harms.

And this, as I will show, is an example of the relentless neoliberal innovation through technology regardless of collateral harms and exploitation of the human’s clinical labour, as capital, through the expansion of anticipatory care programmes.

Thus, in America, logical empiricism encountered not only neoliberalism, but also the American philosophy of William James: radical empiricism, described in more detail below, and its liberalising method, pragmatism.

**Subjective pragmatism and radical empiricism**

Pragmatism is a method of inquiry that is based on a particular philosophy of science, or way-of-knowing, called radical empiricism, first described by William James (1842-1910) in 1912 (James, 1906 Essay II p20). I will briefly outline radical empiricism to contrast it with EBM’s logical empiricism (or logical positivism).

Radical empiricism was a term and philosophy coined by William James, an American philosopher and psychologist of the early twentieth century (it was also termed immediate empiricism by the American philosopher, psychologist and social reformer John Dewey (1859-1952)). It is the basis for a philosophy also known as instrumentalism, or pragmatism.
Unlike the logical empiricism of EBM, with radical empiricism the subject cannot get to know the world any better by thinking, rationalising or calculating on the basis of experiments. Instead, experiments create effects and it is the subjective experience, or thoughts, of those effects that matter. Dewey developed James’ philosophy further for science, and termed it ‘immediate empiricism’.

The key thing here is that only experienced effects are thought to exist and to warrant claims for ‘grounds for belief’ – as a form of truth. And, this is the radical bit, for radical empiricism these experienced effects include the investigator’s impressions of the effects. Therefore, whether the effects are judged to be ‘good’ depends upon the subjective views of the investigator and their acceptability by communal, public opinion.

The consequences of this philosophy are that: a) abstract effects such as opportunity costs and overdiagnosis will not be valued by, or have any effect on, the impressions, or experience, of the investigator; b) the goodness of the effect is a subjective view of the investigator and, as such, tends to be valued only with reference to effects on the specific target of the intervention, and not on any collateral effects; and c) whether any observations made in the inquiry are factual or not becomes irrelevant because it is only the intended consequences of actions that should guide practice.

Pragmatism applies radical empiricism, and was most fully developed by Dewey (for a comprehensive overview see Novack, 1975). Pragmatism puts emphasis on the utility or usefulness of the outcomes of inquiry, taken from the perspective of the investigator. It functions as a theory and method for science and was developed in America in the early twentieth century, particularly by William James and John Dewey (Lewis, 1941; Novack, 1975; Russell, 2004).

The key features of pragmatism are: that inquiry, rather than truth, is the essential objective for human social progress, and truth is the ‘warranted assertion’ of the satisfactory effects of inquiry, actions are defined as a good thing if they have satisfactory effects upon an intended target and are acceptable in the court of public opinion, collateral harms are given less emphasis than intended benefits, society evolves through repetitive inquiry into action, and not through rationality, or by
theorising about mechanisms, and finally, all that exists is only that which is experienced (Russell, 2004 pp723-37).

**Social democratic logical empiricism and neoliberal pragmatism**

It is now possible to discern the indissoluble connection between science and politics. What is at stake here is the value, or meaning, that can be given to the effects of care – in terms of whether those effects can be regarded as consequences that should guide future practice.

Logical empiricism is a positivist philosophy, and, as such, does value harms, as long as they are demonstrable, observable and measurable. And, because it can value harms as a way of guiding future practice, it is less likely to endorse care that causes harm. Therefore, it is less likely to expand care regardless of harm, stretching limited budgets and causing opportunity costs so that care becomes less accessible to many, and especially the poorest. Thus, logical empiricism *tends* to be more supportive of the political goals of collective welfare for all through social democracy.

But, as a positivist philosophy, logical empiricism does not value abstract or non-demonstrable harm, such as overdiagnosis (described in Chapter 1). This weakens its capacity to resist the expansion of harmful forms of care and to be a force for social democracy.

This scientific and political weakness leaves the door wide open for neoliberal politics to simply set up elite committees that are pragmatist, are implicitly radical empiricist, and ensure that new care ‘actions’ are evaluated as satisfactory regardless of all collateral harms including overdiagnosis.

For the American philosopher C. L. Lewis, who analysed the relations between logical positivism and pragmatism: ‘… pragmatism would regard meaning as limited …’, on the other hand, ‘… the pragmatic emphasis upon relevance to some active intent is largely or wholly omitted in logical positivism …’ (Lewis, 1941 p94).

Neoliberal pragmatism controls the public perception of what is good care. Its power depends, in part, on propaganda that a) incites fear and urgency, b) devalues and belittles collateral harms, c) incites the desire of people to consume and c) does not value the unimaginable nature of overdiagnosis.
The radical aspect of radical empiricism is the assumption that subjective thought itself, including elite opinion, is an empirical ‘experience’, or ‘fact’, and therefore has the same impact on empirical scientific conclusions as objective experimental evidence. I argue that, in practice, this assumption treats elite opinion as ‘effective truth’.

This is an objectivisation of the subjective. It leaves open the way for politically inspired neoliberalised pragmatism, which allows powerful elites to use the ‘evidence’ of EBM’s logical empiricism to make acceptable, and to warrant, the continuing expansion of anticipatory forms of care, even whilst it can acknowledge, but at the same time ignore, their collateral harms and overdiagnosis.

This is scientific-political praxis that dominates healthcare even whilst its destructive nature is obscured by a veneer of well-intentioned expert guidance. This veneer functions through persuasive rhetoric – discourse that fixes meanings that support intervention and is normative. That is, it decides, even coerces, how the individual ‘should’ behave and consume care. This normative coercive discourse is illustrated in the next chapter with a case history that describes the UK breast cancer-screening programme.

NOTES

1 Positivism’s standard for what counts as meaningful, in the sense that it should be able to guide belief and future practice, determines both what can be known at all, and how it can be known. Rudolf Carnap, one of positivism’s most notable proponents in the twentieth century, rendered all statements about non-(directly)-observable, or abstract, phenomena, such as for example ‘the laws of nature’, as logically meaningless (Carnap, 1964). I suggest that this emphasis on logic (rationality), and de-emphasis on the non-empirical, leads towards logical positivism (or logical empiricism) becoming the dominant normative way of knowing, as exemplified by EBM. Even though, as I show in this chapter, this philosophy is later subverted, almost surreptitiously, by a radical empiricism. Carnap’s version of positivism shows how it a) influences the theory of EBM, and b) is normative (decides how future practice should be determined), through an emphasis on the ‘acceptable’ use of language to grasp all that can be known of the concrete, material, ‘thing’ world. Notice though that Carnap didn’t dismiss metaphysical thinking entirely.

Carnap, in what seems like a gesture of ‘tolerance’, did suggest science should tolerate consideration of statements that draw on inference and intuition, suggesting that: ‘To
decree dogmatic prohibitions of certain linguistic forms instead of testing them by their success or failure in practical use, is worse than futile; it is positively harmful because it may obstruct scientific progress’. And that, ‘the history of science shows ... such prohibitions based on prejudices deriving from religious, mythological, metaphysical, or other irrational sources, ... slowed up ... developments for shorter or longer periods of time’ (ibid. p12). In this ‘doctrine of tolerance’ for linguistic forms, he advises scientists to provide room for theory, for conjecture, and for inference.

In other words logical positivism, and therefore, the dominant western medical philosophy of so-called Evidence Based medicine (EBM), characterises as meaningless what has been called continental philosophy and thought, such as that of Foucault and Lacan (Gutting, 2005; Nobus, 2002), which rely, albeit with fundamental differences, on the way power discursively constructs consciousness, belief and normative behaviours.

Comte has been attributed with founding a non-religious scientific positivism in an attempt to improve society by reducing ‘delinquency’ after the French Revolution. He used this idea to promote a ‘... revolutionary positivism ...’ Hacking (1990a) and to elevate the normal to, ‘... a state of social perfection, something for which we should all strive ...’ (ibid. p169). Comte was working towards a reduction in social deviancy by determining it in terms of deviations from the state of perfect and, by definition, normal citizenship. The statistical use of positivism, the modern sense in which the term tends to be used, came after Comte, who was ‘antistatistical’ (Hacking, 1990b p78) was developed though the ‘moral analysis’ of population data with reference to crime and suicide in France in the later 1800s: ‘this was positivist science distinguishing fact and value’ (ibid. p78).

Comte’s version of social progress through social engineering was part of a culture for social progress that ‘helped to frame modern discourse on population, eugenics and hygiene’ (ibid. p78). Positivism became an important, if not essential, basis for the scientific approach to social control, including eugenic practices. For example, in France a Eugenics society was formed in 1912.

‘Physician’s constituted more than half the groups founding members. The society’s agenda included government action to manage sexual activity, marriage, birth and life expectancies, via puériculture, social hygiene and eugenics – clear examples of what Michel Foucault would later call ‘Biopower’’ (Fogarty & Osborne, p337)

The Centre for Social Justice (CSJ) report in 2013 by a UK based think tank suggests that provoking ‘negative effects upon their own health, getting arrested, or the prospect of losing their children’ is a way of ‘drawing a previously hard-to-reach group of addicts into treatment’. This is an oppressive and cruel technique that imposes hardship on the already suffering to coerce treatment for a behaviour that has been pathologised both medically and criminally (Centre for Social Justice, 2013 p53).

‘For some addicts, a ‘nudge’ is required before they seek treatment. This can be the negative effects upon their own health, getting arrested, or the prospect of losing their children. The CSJ has also heard that for some who had refused treatment
before, reforms to the welfare system under the current Government have led them
to come forward for help with their addiction’ (ibid. p53 my italics).

5 Foucault provides a useful analysis of neoliberalism in his ‘The Birth of Biopolitics -
‘Lectures at the Collège de France’; 1978-1979. Foucault sees neoliberalism develop
through the transformation in the power of the economic system that took place during the
1970s and 80s, so that it becomes the market that dictates to the state, and the state’s role
to maximise the freedom of the market. Foucault, and others, have suggested that this also
transforms the human being into a homo oeconomicus, a self-entrepreneur, whose life is
devoted to maximising the productivity of the self, but has no time for politics: ‘a human
being who finds its ultimate meaning as an “entrepreneur of himself” in a free and incessant
marketplace’ (Friedli & Stearn, 2015).

6 At the same time this transformation also involved a change in the relation between the
human and the political economic system in which self-entrepreneurship became a mode of
production. Thus, for Foucault, and other more recent philosophers such as Judith Butler,
Etienne Balibar, David Harvey and others, there was a ‘startling economic transition’ in the
1970s, a ‘distinct, historical mutation of capitalism in the 1970s and 80s in which the state
actively supports capitalism … and the primary concern of the human being is self-
entrepreneurship’(Foucault, 2004 p226). Neoliberalism is a positive liberalism in which ‘it is
the market that supervises the state and not the other way round other way round’
(Holloway, 2017 p116).

7 In the western world the dominance of positivist logical empiricism became a major
influence, not just on the sciences, but on political economy and social policy too. This can
be seen in the impact of the thinkers of the Vienna Circle (described earlier) on politics and
economic policy, especially in the USA in the 1940s and 50s. The school of positivism and
logical empiricism also found its way into the Chicago school of economics and the
development of neoliberalism, particularly through the work of Hayek, who saw these
positivist methods as a way of shaping public opinion. ‘Public opinion … is the work of men
like ourselves, the economists and political philosophers of the past few generations, who
have created the political climate in which the politicians of our time must move …’ Creath
(2017).

8 In North America the philosophy of logical positivism developed into a policy of
pragmatism which was was then promoted by some of the Vienna Circle and The Chicago
School, such as Hayek and Mises, as a means of implementing political neoliberalism (Nik-
Kah, 2016). Under this policy, the freedom to make personal profit trumped freedom of the
collective people from exploitation. Thus for the UK prime minister, Thatcher, and USA
president Reagan in the 1980s, there was ‘no such thing as society, only individuals’.

9 Neoliberalism resists any state control that aspired to redistribute wealth as in the social
democratic ordoliberalism of Germany (Foucault, 2004). Briefly, ordoliberalism was a
political model in Germany, in the 1930s, which favoured regulation of the market to
increase collective justice and social equality. Ordoliberalism has been termed a
coordinated market economy to contrast it with neoliberalism’s liberal market economy.
Neoliberalism seeks to undo the social democratic movements that took place after the
Second World War: America’s New Deal, and the UK’s Beveridge Plan (ibid. p216). Neoliberalism sees the worker as an active economic actor, a *homo-oeconomicus* that is an entrepreneur of the self, with an income stream derived from her own human capital.

Foucault, I suggest, foresaw the proliferation and expansion of pervasive anticipatory healthcare, in which there is promise of surplus life apparently for free, as long as you are prepared to give up your body, or your genetic make up, and where we ‘need to see a return’ on our human capital (ibid. 227):

‘Now obviously we do not have to pay for the body we have, or we do not need to pay for our genetic make up. It costs nothing - and yet, we need to see ... and we can easily imagine something like this occuring (I am just engaging in a bit of science fiction here, it is a kind of problematic which is currently becoming pervasive)’ (ibid. p227)
Science and politics, a case history

Breast cancer screening

Introduction

In this chapter I provide an example to help the reader understand the way neoliberal pragmatism works in practice. And, although this is an example using cancer screening, the principles apply just as well to other fields of care such as screening for dementia (Yokomizo, 2014), psychological screening for employability (Gayle, 2015), or the expansion of diagnostic categories for apparently new forms of mental illness (Wakefield, 2016).

The elite expert decision that the UK breast cancer screening programme is ‘a good thing’ is described in terms of its persuasive rhetoric and how this hides an underlying coercive neoliberal pragmatism. The rhetoric ignores the impossibility of valuing overdiagnosis as a personal harm and represses the meaning of the collateral harms as harms that can be valued as harm.

First, to remind the reader: pragmatism is a practical method for deciding on and implementing social programmes warranted by a philosophy of science, or way-of-knowing, called radical empiricism that counts expert opinion as if it is an empirical fact. According to pragmatism social progress is made through trial and error, that is to say, by inquiries into the effects of actions to solve problems.

In 1986, the UK government commissioned an inquiry into the effects of breast cancer screening. This produced the Forrest Report, which judged screening to be a good thing. As a result, screening was rolled out nationally (Forrest, 1986), although not without controversy (Baum, 2016).
Background to the breast cancer screening controversy

Age-specific all-cause mortality rates

Two opposing camps disagree over whether breast cancer screening is justified or not. These have been called a) the pro-screeners (for example see: Marmot, 2013b, 2013c) and b) the screening sceptics (for example: Jørgensen, Gøtzsche, & J, 2011). At stake here is the issue of benefit and harm, and one factor of importance here is the effect of screening on the all-cause age-specific mortality rates.

Recently, the Swiss Medical Board has recommended that breast cancer screening be phased out in Switzerland (Prasad, Lenzer, & Newman, 2016). This is mainly because there is no clear evidence of a reduction in overall age-specific mortality rates with mammography screening, that is, the rate of deaths from all-causes including breast cancer (ibid.):

‘A summary of the Swiss medical board’s decision not to recommend mammography shows that for every 1000 women who undergo population-based screening one breast cancer death is averted (from five to four), while non-breast cancer deaths either remain at 39 or may increase to 40. If non-breast cancer deaths remain the same, a woman must weigh net benefit against harms. If screening increases non-breast cancer deaths to 40, women would simply be trading one type of death for another, at the cost of serious morbidity, anxiety, and expense. Women should be told that to date, with over 600 000 women studied, there is no clear evidence of a reduction in overall age-specific mortality rates with mammography screening.’ (ibid. p2)

Now, if the age-specific all-cause mortality rate (death rates due to all causes including breast cancer) is not reduced in those screened whilst breast cancer death rates are reduced in those screened then some extra deaths must be occurring to offset the reduction in breast cancer deaths. As noted in chapter 1, it is possible that this is due to some unknown confounding factor – some difference between the screened and the unscreened populations affecting survival rates. Thus, it is, in theory, possible that the screened population has characteristics associated with a higher mortality rate that might explain the failure of screening to reduce the all-cause mortality rate in the
screened population compared to the unscreened population. However, it is known that there is a lower uptake of breast cancer screening in more deprived areas with social classes associated with higher mortality rates compared to those from wealthier social classes, which at least suggests that the screened population is more likely to already have baseline characteristics associated with a lower (rather than a higher) all-cause mortality rate than unscreened populations (Jack, 2013). On the other hand it is at least plausible that, since screening uses x-ray technology and invasive procedures that are known to cause harm, the screening and treatment itself may be responsible for causing excess deaths in the screened population (Baum, 2013). And, indeed, there is increasing evidence that mammography is causing excess cancers (Corcos, 2017; Nelson, 2016).

Screening-sceptics continue to argue it is reasonable to conclude that screening is likely to cause net harms, and causes excessive overdiagnosis, and even deaths, due to investigations and treatments, so that the sacrifice imposed means that screening is at present unjustified (Baum, 2013).

Baum has described the possible causes for these extra deaths in terms of predictable side effects of radiation on the circulation leading to premature heart disease (Baum, 2013).

On the other hand, I suggest, pro-screeners argue that the evidence that screening has no effect on reducing mortality rates is weak, and, in any case, preventing breast cancer deaths must always be worthwhile, a decision only requiring that the collateral harms have been characterised, measured and publicised (Marmot, 2013a). It appears, as I show later in this chapter, that those in power are prepared to authorise a programme of care that may be causing net harm, on the selective basis of a) achieving reduction in one cause of death, and b) by not acknowledging and valuing the collateral harms as harms, including deaths due to other causes and possibly even due to the programme itself.

**Overdiagnosis**

Some healthcare scientists are concerned about the scale of harms being caused by and have questioned whether screening should continue. Studies have found an overdiagnosis rate of up to 50 per cent, and there is increasing evidence for these
figures (Jørgensen & Gøtzsche, 2013). More recent studies reinforce this estimate: ‘Overdiagnosis has increased over time with the extension of screening to women aged 70-75, and with the replacement of film-based mammography by digital mammography. In 2009-11, 51% of in situ tumours and stage 1 cancers found in women aged 50-74 and 52% of screen detected cancers would represent overdiagnosis’ (Autier, 2017).

The so-called screening-sceptics, in 2012, brought these mathematically demonstrable measures of overdiagnosis to the attention of the government’s cancer experts and scientists (Gøtzsche & Nielsen, 2011). This, eventually, forced the UK government to convene the panel that conducted the breast cancer screening review (Bewley, 2013; Marmot, 2012).

The cancer experts, and the state, were forced to perform a review in order ‘to settle the matter’, to take overdiagnosis into consideration, and to respond to the concerns. The resulting review provided: a) a somewhat reduced ‘figure’ for overdiagnosis, more like a 30 per cent overdiagnosis rate, rather than 50 per cent, (corresponding, in the UK, to 4,000, rather than 7,500, women a year overdiagnosed); and despite this, b) a declaration that the screening programme should continue: ‘… for every breast cancer death prevented about three overdiagnosed cases will be identified and treated … the panel concludes the UK breast screening programmes confer significant benefit and should continue’ (Marmot, 2012).

The review in 2012 was expert and elite. The review also had added authority because the government commissioned it. The review’s conclusion was therefore effectively juridical, and would subsequently dictate policy as ‘best’ practice.

Some health scientists and clinicians, including sceptics, ‘were delighted that the Marmot panel apparently used good scientific methods to reach their conclusions, and because it, at least, acknowledged overdiagnosis as a fact (Bewley, 2017 personal communication).

However, even with a conservative 30 per cent overdiagnosis estimate, screening was still considered a good thing and that it should continue.
The decision to continue screening and neoliberal pragmatism

The panel’s judgement in 2012 (Marmot, 2012) that screening is a good thing is consistent with a) a radical empiricist philosophy of science, b) a pragmatist method for evaluating effectiveness and c) neoliberal demands for increased industrial and human productivity.

The panel’s judgment consists of its ‘thought’, which is defined, under radical empiricism, as their subjective experience of the effects of screening, and as an experience it is admissible as an empirical evidential fact that warrants their assertion that screening is actually a good thing.

At the same time, the political assessment in this case was that the public would also accept this judgment, so that, for pragmatism, the requirements of the solution to the problem are fulfilled satisfactorily, and the screening programme became national policy.

Radical empiricism and pragmatism do not demand that the inquirers necessarily value collateral harms as part of their judgment of screening’s effects. Under pragmatism, only the intended effects on breast cancer death reduction are valued.

In this book History of Western Philosophy Bertrand Russell provides two short essays on the pragmatism of William James and John Dewey (Russell, 2004). He provides a telling example of how, for pragmatism, the truth of historical facts as an actual past event (such as overdiagnosis, where an apparently screen ‘real’ cancer diagnosis never causes harm), is actually irrelevant when it comes to deciding future actions – all that matters is the effect the diagnosis has on future events. And, in order to ensure that it is the desired effect (saving lives from cancer deaths) that determines future action it is possible to ‘arrange a social environment’ (say, through persuasive rhetoric, and vested interests in social relations and power) that makes certain historical facts, (such as say overdiagnosis or other events) irrelevant. As Russell goes on to say:

‘Did Caesar cross the Rubicon? (Which, I suggest, begs the question, whether in our case, a false positive, or overdiagnosed, screen diagnosis can ever be considered a historical fact at all). I should regard an affirmative answer as
unalterably necessitated by a past event. Dr. Dewey would decide whether to say yes or no by an appraisal of future events, … I can, if I have enough skill and power, arrange a social environment (for example, in our case ‘independent’ scientific reviews into the harms and benefits of cancer screening) in which the statement that he did not cross the Rubicon (or that screen diagnoses are always ‘real’ cancers, which untreated will kill you) will have warranted assertability… so as to make a negative answer the more satisfactory (that screen diagnoses are never false positives, never regress, and don’t lead to unacceptable overdiagnosis, so that screening can still be considered a good thing despite overdiagnosis).’ (Russell, 2004 p736 my additions in brackets)

Note that pragmatism’s ‘arrangement of the social environment’ may also tend to depersonalise by emphasising population-based and intended outcomes, making other population-based measures of unintended outcomes, such as collateral harms, easier to discount: ‘In Dewey, as in current science and ethics, there is a pervasive quasi-Hegelian tendency to dissolve the individual into his social functions …’ (Santayana cited in Russell, 2004 p737).

Thus, in Russell’s terms, in order to ensure that the desired future effect of saving lives from cancer is able to decide future action (that screening is a good thing), social arrangements (such as an elite review) are organised that fail to acknowledge and value as historical fact the value of harm as such of: a) the lack of demonstrable reduction of overall mortality-- which means that potential deaths due to the screening programme, mammography and surgery themselves are not valued; b) direct collateral harms such as the loss of breasts, side effects of treatment, and the inconvenience, trauma, and anxiety associated with testing; and c) invisible but actual collateral harm, such as overdiagnosis.

The independent expert review of screening, appointed by the UK government, its rhetoric, and its conclusion that screening is a good thing, is consistent with a neoliberal capitalist and pragmatist ideology at work. The neoliberal pragmatist ideology is based on an imperative to ensure innovation and on subjective expert thoughts or impressions. Neoliberal pragmatism works to ensure that commodities are free to be produced, without limit, and to be marketed free of government
regulation. Note that this would be at odds with the commonly held, but I suggest, illusory belief that new technologies are warranted by an objective logical empiricism and political regulation with social democratic potential, as described in chapter 2. Thus, in this instance at least, health care products such as breast cancer screening are evaluated in terms of the intended effect on targets, as a social function: assumed to be in society’s best interests, and, therefore, are warranted as ‘a good thing’, regardless of their unintended collateral harms.

Consider a statement during a TV interview by a cancer expert in 2012, made by Professor David Cameron, who was on the so-called independent review panel. Notice that this is a male commenting on the value of a programme aimed exclusively at women, suggesting a degree of possible patriarchy and even what might be called gender appropriation, he claims: ‘I personally would prefer to avoid a breast cancer death … and the risk that I might have a cancer overdiagnosed and therefore treated is one I would be prepared to take’ (BBC, 2012a BBC News at Six, 3 minute clip).

This statement reflects the pragmatist attitude and effectively privileges the active intent of the programme, preventing cancer deaths at the expense of collateral harms that would, if counted and valued as harm as such, negate the conclusion that screening is a ‘good thing’.

I showed in chapter 2 that science and politics are indissolubly linked. On the one hand, neoliberalism (by which I mean neoliberal capitalism) and pragmatism are mutually dependent and synergistic ideologies. This is because, briefly put, the neoliberal idea of a market free from governmental regulation corresponds well with the pragmatist idea of warranting innovations evaluated on the basis of future intended effects rather than consideration of collateral harms. Conversely, on the other hand, logical empiricism, which has the potential to value empirical harms and benefits equally as evidence to guide future practice, would hinder the ‘freedom’ of neoliberal pragmatism to only value intended effects. This is why I have suggested that health scientists who adhere to a logical empirical philosophy as a way of knowing can also aspire to social democratic political aims.

As an ideal-type, then, social democratic-logical empiricist scientists value the welfare of the whole population, and not just the relatively few who would actually
benefit from having a cancer death prevented. They are also concerned about those harmed by the process. So, they attempt to value overdiagnosis, as harm as such, and at a population level, they attempt to cite it as a factor in determining whether screening is a good thing (Jørgensen et al., 2011).

However, the ‘ideal’ logical empiricists are unable to make overdiagnosis count as value-able by: a) its positivist scientific philosophy: logical empiricism; and b) at an individual patient level. This is because overdiagnosis is not empirical evidence because it is not observable sense-data, and is neither finite nor discrete. And, overdiagnosis is measureable only at a population level: it is never individually and subjectively experienced. So, in the end, because it is the neoliberal pragmatists who have the power to make the final decision, the attempt to compute value of life of those harmed by overdiagnosis fails to guide practice. The neoliberal pragmatists are only swayed by limited active intent, that is, for example, by saving lives from breast cancer deaths.

Overdiagnosis is a universal feature of all forms of anticipatory care and treatments. And, as an abstract and never-experienced event, it cannot be consciously thought of as something personally imaginable or relevant. So, therefore, the assumption that knowing and agreeing on the nature and magnitude of overdiagnosis is sufficient to make the screening process fair, and democratic, functions as a convenient fiction.

Continuing anticipatory modes of care will make the citizen increasingly vulnerable to being positioned as limitless human capital or clinical labour for a neoliberalised market. This is a mode of care that goes beyond care, as that which protects health, and this mode of care is warranted not by a social democratic objective logical empiricism but by neoliberal subjective pragmatism.

The way rhetoric is used to warrant intervention by producing some normative meanings whilst repressing other meanings is illustrated in the next chapter where overdiagnosis, ‘real’ cancer and the boundary between normality and pathology are considered.
Language, harm and overdiagnosis, a case history of ‘real’ cancer

Introduction

This chapter uses the UK government’s breast cancer screening programme to illustrate the ways in which public opinion is being influenced. I show how the meaning of the terms used for harm is changed by the use of rhetoric so that they are belittled and devalued, and how overdiagnosis is effectively side-lined as a problem. I also show how the name ‘real’ cancer functions discursively, that is, through expert rhetoric or discourse, to fix meaning to screen-diagnosed cancer as accurate and to screening as a good thing.

In this chapter I provide three examples of the way language is aligned with neoliberal pragmatist ideals, and used as propaganda, by scientist-politicians. In these examples language is used to: a) impose particular beliefs about care; b) reinforce the idea that test results are always true and never false; and c) incite fear and urgent action.

I hope to show how political ideologies, such as neoliberalism, use language in ways that shape conscious thought, and public opinion, and that there are important unconscious factors at play in this process. This, then, introduces a different way of thinking about the human being and her subjectivity, that is, the way the individual makes sense of her self and social relations. This is a theme taken up in later chapters.

Recap

In the last chapter I argued that overdiagnosis can never be imagined as a personally relevant, or even experience-able, harmful event. And, therefore, it cannot ever be valued as personal harm. And, so, simply providing information to individuals about overdiagnosis, as if they will then be able to make a balanced decision, does not
enable people to make decisions taking overdiagnosis into account as a personal harm.

However, there is an argument that, as long as people can be told about the associated ‘morbidity’, that is, the collateral harms, including overdiagnosis, then anticipatory care, such as screening, should continue to be offered to the public.

This argument implies that all that is necessary to decide to continue screening is: a) to show effect on the intended target, for example, that cancer deaths are reduced; and b) to agree on the ‘nature and magnitude’ of those morbidities, so that ‘balanced’ information about the ‘pros and cons’ can be provided to the public in a ‘fair’ way.

That argument is a convenient fiction that supports neoliberal pragmatism’s manipulation of both professional and public opinion. It is, of course, important to know about anticipatory care’s harms, but the questions then arising are: How is this knowledge framed and managed? How do the advertisers present information about harms? How is public opinion about anticipatory care influenced by the way it is advertised?

In previous chapters I have shown that policies deciding what is good care, at national and professional institutional levels, are consistent with: a) a scientific way-of-knowing called radical empiricism, and b) a method of using that knowledge to guide practice, in the name of social progress, called pragmatism.

For William James’s radical empiricism, the ‘truth’ of the experienced effects of any action is to be sought in the observer’s impressions of, or thoughts about, those effects (James, 1906). In other words, those thoughts, themselves, are regarded as empirical experience, that is, as facts that should guide future practice.

John Dewey’s pragmatism puts radical empiricism into practice, with the provisos: a) that the observer only considers the effect on the intended target, for example, breast cancer deaths; and b) the practice must be acceptable in the court of public opinion (Novack, 1975).

And, at the same time this pragmatism is a mechanism for producing a flow of new commodities for a neoliberal capitalism, and for shaping public opinion to accept and
even desire those commodities. Shaping public opinion is a method of wielding political power. As Hayek, one of the Chicago school, put it: 'Public opinion … is the work of men like ourselves: the economists and political philosophers of the past few generations …' (Nik-Kah, 2016).

Hayek is referring to the way pragmatism shapes beliefs to serve neoliberal capitalism. And shaping public opinion is shaping public belief about what works, and about what is effective: knowledge that should count and guide practice.

**Altering the meaning of overdiagnosis and shaping public opinion**

‘Morbidities’ is a technical term for anticipated collateral harms, or side effects, due to cancer screening, diagnosis and treatment. In the words of the UK government’s independent review of the benefits and harms of breast cancer screening these collateral harms include:

‘Pain from mammography … being recalled for repeat mammography or biopsy … psychological distress … *well recognised* morbidities … associated with surgery, adjuvant endocrine therapy, chemotherapy, and radiotherapy … and … the *well documented* adverse psychological results of a breast cancer diagnosis and subsequent treatment’ (Marmot, 2012 p1784 my italics).

I suggest that the language used here frames these collateral harms in terms of how well characterised and documented they are, rather than in terms that value, their harmfulness as such. There is, at least, I suggest, a kind of ambivalence of concern, where a) the value attributed to direct observable harms is being neglected and diminished because they are foreseeable and ‘offset’; and where b) the value of overdiagnosis, as harm, where there is no possibility of it ‘being offset’ by the chance of reduced mortality, is also effectively reduced by identifying and emphasising its magnitude over its harmful nature.

**Overdiagnosis**

The review presents overdiagnosis as a concern: ‘… these harms’, the morbidities described above, ‘are mostly foreseeable and quantifiable. The main *concern* is for
women whose cancer is overdiagnosed … for whom the morbidities are not offset by any potential gain from reduced mortality’ (ibid. p1784 my italics).

However, subsequently, the government appointed ‘Cancer Tsar’ Professor Richards, who referred to overdiagnosis in a media interview:

‘There is this problem, overdiagnosis [where] if a cancer diagnosis is given [it] would never have troubled her in her lifetime … It is a real cancer … and we’ve got a figure for that of 4,000 … that means we can present balanced information to the public so that, when we invite them for screening, we can show them the pros and cons in a fair manner.’ (BBC, 2012b my italics)

This reassuring statement can be contrasted with the review’s apparent ‘concern’. That concern about overdiagnosis now seems to have been neutralised by having established ‘a figure for that’, that is, for the magnitude of overdiagnosis (even though the review also states: ‘these figures are best estimates from inadequate data’ and ‘the figures cited give a false impression of accuracy’ (Marmot, 2012 p1784).

This raises a question: Is this language that is reversing, or at least negating, the meaning of overdiagnosis as a harm as such? Is the meaning being transformed from: a) harm that is a concern because, for the overdiagnosed individual, there is no health benefit to offset harm, a fact which might negate the argument that screening is a good thing; into, b) a reassuringly known ‘figure’, a number that, simply because it is known, can be used to demonstrate how fair and transparent the programme is, thereby neutralising concern and shaping public opinion to support the idea that screening is a good thing?¹

The term ‘overdiagnosis’, first, in the review findings, signifies a concern about a collateral harm associated with zero potential benefit. Then, second, overdiagnosis is transformed to mean, or signify, a reassurance, that the screening programme is transparent, balanced, and therefore fair.

The scientist-politician’s rhetoric uses language that is consistent with radical empiricism. To remind the reader, for radical empiricism, it is the thoughts, or impressions, of the experienced effects of the action, screening, that counts as the
empirical fact. Thus, expert impressions become sufficient to warrant the assertion that screening is a good thing.

The *reversal* of the meaning of overdiagnosis: from ‘a concern’ into a reassuringly known figure, sells the programme to both professional carers and the public. This act is consistent with a scientific-political ideology based on belief in the necessity for ‘progress’ through a) innovation and technology and b) action to tackle intended targets such as cancer, through anticipatory early diagnosis, regardless of collateral harms.

The change in meaning serves to persuade public opinion that screening is worthwhile. And, to remind the reader, this is consistent with both: a) neoliberal political demand for programmes of care that increase economic productivity; and b) a pragmatist requirement that programmes of care are acceptable in the court of public opinion.

**Making meaning unconscious or ungraspable**

It is worth noting that the change in meaning of ‘overdiagnosis’ demands a belief in the benefit of being screened. This belief depends upon the way the meaning of overdiagnosis, as harm, is made ungraspable, that is, as something that might indicate screening is not a good thing.

This is an example of the general way in which conscious thought-impressions, as beliefs, are forged through discourses that make other thoughts and knowledge unconscious, or as it is sometimes put, making knowledge, that is known, un-known or disavowed.

**Altering the meaning of diagnostic names and public opinion**

The idea of overdiagnosis, and its undeniability as harm, even if ‘such cases cannot be individually identified’ (Marmot, 2012 p1784), casts doubt on the diagnosis of cancer by screening in the first place. If it is cancer, how is it possible that it would never harm me if it weren’t treated? This is a possibility that people invited for screening find difficult to comprehend (Jolyn et al., 2013). As discussed in chapter one, the individual may, of course, die of something else before succumbing to the cancer, but
the cancer also, sometimes, simply never progresses as expected, to cause symptoms, that is, it never grows or invades, or it may even shrink and regress (Zahl PH, 2008).

However, the doubt created by the fact of overdiagnosis is bad publicity for the screening programme, and may lead to a reduction in screening uptake. This may also lead to further calls for the programme to be stopped, as has happened in Switzerland (Biller-Andorno, 2014). And, in addition, it may lead to calls, under some circumstances, for the name ‘cancer’, when applied to screen diagnoses, to be dropped altogether (Dunn, 2013; Esserman, 2019; Esserman, Thompson, & Reid, 2013; Esserman, 2015).²

The problem of overdiagnosis caused by anticipatory care of the asymptomatic illustrates well a universal ‘paradox in the sciences of life’ made evident by ‘the threshold marked’ by ‘the specificity of disease’ (Foucault, 1985 p474). By the specificity of disease I suggest Foucault refers to the accuracy of a distinction between the normal (as asymptomatic and that which will not lead to symptoms) and the pathological (as either symptomatic and/or that which will lead to symptoms).

However, the concept of disease has been, and is, the subject of much debate among medical philosophers (Canguilhem, 1991; Schramme, 2014). For, the purposes of this chapter, I will use the label disease to signify future suffering, or at least an existing or certain future deterioration in an individual’s perception of his or her capacity to function. And, my standpoint is that particular diseases are discursively and socially constructed via neoliberal pragmatism. However, this isn’t a universal or uncontested view. For some, such as Boorse, the concept of disease is theorised in terms of deviation from a population-based statistical norm, even if such a disease may never cause symptoms even if left untreated, that is, is non-harmful, ever, to an individual (Boorse, 1977).
Boorse’s Bio-Statistical-Theory (BST) and the concept of disease

Here, I provide a brief review of medical philosophical approaches to the concept of disease, as far as they are relevant to the mis-application of disease status to the overdiagnosed and understanding the effects of the real cancer paradox.

See chapter 2 for a constructivist account of disease and health, where health is seen as an individual’s potential to re-set his or her own norms in the face of life’s and the environment’s inconstancies, and where diagnosis of disease always involves a value assertion. Here, I will give a review of the debates over the concept of disease from a so-called naturalist medical philosophical, or in other words an empirical and positivist perspective.

To remind the reader, the real cancer paradox is that screen diagnosed cancers are referred to as real cancers even when some screen diagnoses are overdiagnosed as cancer and apparently harmful, but will never cause harm even if untreated. The question then raised by the paradox is that if the diagnosis looks like cancer but does not behave like cancer how can it, and why would it, be called cancer? The answer lies partly in the way cancer is labelled as a disease, and how the term disease tends to be defined, used and understood, albeit implicitly. I argue that the way the terms disease and ‘real’ cancer are used in debates about overdiagnosis increases the potential for harm through anticipatory care by screening the asymptomatic.

I will discuss: a) the problems with the influential bio-statistical theoretical (BST) concept of disease, in relation to b) the way the term ‘real’ cancer is applied to all cancer screening diagnoses, and c) why this discriminates against the overdiagnosed.

I want to outline the main features of, and problems with, the dominant philosophy behind the concept of disease that appears to underly and is traditionally accepted by medical practice. This is known as the objectivist, or naturalist, bio-statistical theory (BST), of health and disease. This was originally developed by Boorse (Boorse, 1977). It has important implications for overdiagnosis and screening, and has been the subject of much debate and criticism (for an overview see Schramme, 2014). Here, I focus mostly on Kingma’s critique (Kingma, 2007), as well as developing my own critique of the theory’s normative discursive power, and on the way BST is used
by some to justify labelling overdiagnosis as *mal-detected* disease (Rogers & Mintzker, 2016).

Three problems with this biostatistical, ostensibly objective and value free, approach are identified. These problems are: a) the choice of reference classes against which statistical typicality is judged; b) the specification of a cut off between a so-called normal and so-called pathological state applied to, and chosen to discriminate among and between the qualitative continuum of biological tissue appearances, human thoughts and behaviours, and c) the discursive power of a name: ‘disease’, to incite fear, and to persuade and elicit beliefs and decisions to consume healthcare.

I will show that what is claimed to be a value-free positivist concept for disease, apparently based purely on objective or natural empirical science, is not only a) unable to justify the specification of visual diagnostic signs as a basis for screen diagnosing (asymptomatic) cancer, but is, b) also dependent on value judgments about the reference classes by which disease is diagnosed and c) has a positive (directing) influence that de- or under-values overdiagnosis as a harm as such, and so warrants and promotes interventions.

In addition, I will show that, therefore, this concept discriminates against, and thereby pathologises, people overdiagnosed by cancer screening who are at the same time both a) invisible to healthcare, as well as b) unable to identify themselves as overdiagnosed.

Boorse’s theoretical concept of disease isn’t often explicitly stated or even acknowledged in debates on overdiagnosis, but it is nonetheless the dominant theory of disease in the philosophy of medicine, against which other concepts tend to be judged: ‘ … it can be demanded that philosophers of medicine must now either work within Boorse’s theory or explain why not’ (Rogers & Mintzker, 2016).

The basis of Boorse’s BST is to use statistical typicality according to *reference classes limited to age, sex, race and species* in order to define normality and abnormality by imposing a differentiation upon the organism’s parts and processes that work to maintain survival and reproduction. Thus:
‘… health is normal species functioning, which is the statistically typical contribution of all the organism's parts and processes to the organism's overall goals of survival and reproduction. The group with respect to which a contribution is statistically typical is the reference class, specifically an age group of a sex of a race of a species (Boorse, 1977 p555).’

Although Boorse refers to health here, this is on the basis whereby he refers to health as the absence of disease, so here I will focus on the term disease. Notice that this concept, to be useful in practice, requires the organism’s parts and processes (its biological functions) to be empirically identifiable, that is to say, to be finite, discrete and measureable. If, then, BST is applied to screening diagnoses then it is also assumed that the signs of cancer must be empirical: finite, discrete and measureable, whereas, on the contrary, they are purely pictorial and visual and vary visually in a qualitative continuum that defies empirical discrimination.

It is worth noting that Boorse’s BST is closely analagous to Auguste Comte’s positivism of the 19th century, which was based on a statistical basis for normality, against which deviancy, such as criminal behaviour, could be detected and measured and corrected, and that this influenced Broussais’ principle of disease as ‘excess’ beyond a norm, caused by ‘irritation’, as discussed in chapter 4 (Hacking, 1990a pp164-8).

I suggest that the bio-statistical theory (BST) of disease, based on age, sex, race and species, medicalises everybody, universally, according to all other possible reference classes, such as say sexuality, or gender preference, or even the screen-diagnosed. For example, tooth decay is so common that according to BST it is not a disease state, but, on the other hand, homosexuality is uncommon enough for it to be a disease according to BST. The point being, that everybody is now an object of medicalised discrimination according to all human qualities apart from age, sex and race, as if the medical judgment about the state of a person as diseased or non-diseased is independent of social values and processes. This is why BST classifies homosexuality as a disease, as if this label is independent of, and does not influence, social value judgments. This is what I mean by medicalisation: it is the biophysical homologue of psychologisation. Where, psychologisation is the assumption that a person’s values, beliefs and/or behaviours can be extracted from them, like an
empirical sign, and used to discriminate between individuals medically, as if these beliefs and values are independent of social processes (Parker, 2015a pp57-8).

It has been argued by some that mainstream traditional and ‘accepted’ practice is that final screen diagnoses are based on an accepted ‘gold standard’ for diagnosis of disease, and that, therefore, such diagnoses of disease are never false positives (Rogers & Mintzker, 2016). That is, the diagnoses of cancer by screening are never simply wrong or incorrect as such, but are always disease, but just sometimes, as in the case of overdiagnosis, a case of what Rogers and Mintzker (2016) have coined *mal-detection* of ‘real’ cancer. This *mal*-detection is where detection has ‘gone wrong’ or malfunctioned as it were, but where this *mal*-detected diagnosis still functions, correctly it is implied, to indicate the need for treatment. Notice that the prefix *mal*-here implies a kind of error but not one sufficient to be classed as negating the diagnosis completely as wrong or incorrect or say, as a mis-diagnosis, or false positive.

I won’t go into detail here, but notice that this use of language can be used to make excuses for causing harm. This was referred to by the ordinary language philosopher JL Austin in ‘A Plea for Excuses’ (1956). Austin noted, famously, using an apocryphal tale of two donkeys, that the word ‘accident’ is used to absolve a person for moral responsibility for an action, whereas the word ‘mistake’ allows some moral responsibility to remain attached to a person. I suggest that the term *mal*-detection functions in the context here like the word accident. It is as if overdiagnosis has just occurred by chance, whereas I think the term should be *mis-*detection where overdiagnosis is signified as the (moral) responsibility of the care-providers.

Some have argued that the use of the so-called naturalist (or objectivist) concept of disease (that is, the concept of disease according to Boorse’s biostatistical theory, BST) to class overdiagnosis as disease, albeit *mal*-detected, encourages the expansion of harms due to overdiagnosis (Hofmann, 2017). Thus, naming overdiagnosed tissue as disease: a) signifies being correctly treated for a disease and, b) conversely, fails to recognise and signify that being over-diagnosed is to have a non-harmful finding unnecessarily treated, and so to suffer personal harm. Therefore calling overdiagnosis disease or, say, ‘real’ cancer, permits and enables screening programmes to expand, and hence overdiagnosis to continue to increase.
Hofmann has suggested, as one way to reduce overdiagnosis, that more personally relevant information should be provided to individuals about their risk of being overdiagnosed if the screening test is positive for cancer (Hofmann, 2017). But, in addition, I suggest that overdiagnosis is potentially being encouraged and increased by the discursive and persuasive power of the name disease applied to overdiagnosis, as for example, by naming all screen diagnoses as ‘real’ cancer. This is because it signifies the diagnosis as essentially correct, in need of treatment and so incites fear and demands compliance.

Kingma shows convincingly that Boorse’s BST is internally value-laden because it restricts the reference classes to age, sex, race and species. This choice of reference class means, for example, that homosexuality is classed by BST as disease, albeit not necessarily as a bad thing, or in need of treatment. In other words BST discriminates against, or medicalises, states of being that are not age, sex, race or species defined.

By extension, then, overdiagnosis is classed as disease because the appearance of the examined feature is classed as statistically atypical for a person of a given age and sex. For example, this might be a screen-diagnosed breast cancer diagnosis. Now, notwithstanding the impossibility of empirically identifying a cut-off that can distinguish between harmful and non-harmful histological (visual and pictorial) features, this means that the (always unidentifiable) overdiagnosed individual is always classified as diseased and therefore, it is implied, correctly treated. In this sense the overdiagnosed, even though they can never be individually identified, are discriminated against, even though they are unaware of it. If the population of people diagnosed with cancer by screening was identified and their tissue appearances classified in some way, then the tissue of those overdiagnosed would be seen as not ‘statistically’ atypical within this population and therefore not as disease. To not identify and classify the asymptomatic screen-diagnosed, as a reference class is to medicalise and discriminate against the overdiagnosed.

“Note that it does not refute naturalism to point out that the concept of disease is sometimes misapplied, so that we think people are sick but discover that they are not. In such cases (e.g. homosexuality) the explanation for why it happened may be that our values caused the initial judgment, but that does not
show that the concept of disease is constructivist, rather than naturalist. No concept is correctly applied every time.” (Murphy, 2015 my addition in italics)

But I suggest that this ignores the harms that result from what is in retrospect a maldetection or mal-application, when the concept of disease is defined, as with BST, that includes diagnoses that will never cause harm. In this case the concept of disease is discursively applied and, in the case of anticipatory care is always constructivist, in the sense that a condition is diagnosed as disease according to social value judgments, and, then, subsequently, a biological cause is sought to validate or construct the disease as a fully fledged medical entity. And, I argue that that this constructivism happens with anticipatory care when the naturalist concept of disease, as described by Hofman above as harmful, claims that a screen diagnosis based on a statistical definition of normality is a ‘natural kind’: disease that is harmful, and is repeatedly mis-applied. This is one of the ways that anticipatory care practices are able to keep expanding.

Very briefly, in this thesis, (as elaborated in chapter 5), I argue that disease diagnosed by anticipatory screening is constructivist. This is because medical thinking plays a role in human society partly because it is influenced by neoliberal (capitalist) pragmatism, which shapes medical subjectivity and thinking (conscious beliefs) in ways that incite desires to innovate and intervene according to limited intentions and de-value collateral harms (which are made unconscious).

Suppose, then, we accept, for argument’s sake, the possibility that a concept of disease may be defined and used in accepted medical usage to mean: a) a condition that leads to a deterioration in a person’s capacity to function such that this feels by the person to be a worsening condition, and b) that this is due to an abnormality of typical biological function. This is one form of a naturalist concept of disease. This concept of disease is supported by Lowy’s (2010) historical account of the development of cancer diagnoses. Then, according to this concept of disease, it is mis-applied when it comes to anticipatory diagnostic care applied to the asymptomatic as, for example, with screen cancer diagnoses. (Note, however, the use of the concept of disease for risk factors like blood pressure is a contested extension of the label ‘disease’.)
In the case of homosexuality a reference class, sexuality, was excluded, because of social value judgments, when considering sexual preferences leading to the conclusion that homosexuality was atypical and therefore, according to Boorse’s BST, a disease.

Here, in the case of screen cancer diagnoses, the reference class of the screen-diagnosed patients is also excluded, when it comes to diagnosing cancer. It is unidentifiable in individual cases but exists, and is in effect excluded as a reference class by the social value judgment that: ‘screening asymptomatic individuals for cancer diagnoses specific early cancers and leads to the prevention specific cancer deaths and so is a good thing’. But, according to the concept of disease described above, where they do not, and are not going to, suffer from a deteriorating capacity to function, the overdiagnosed are not diseased. Just as, for the same reason, a homosexual is not suffering from a disease.

Suppose however that the overdiagnosed, as with the homosexual population, were to be included as a reference class against which the overdiagnosed statistical typicality and disease status could be judged. The overdiagnosed would not then be considered diseased because they are not statistically abnormal within this reference class. This would still be consistent with the naturalist definition of disease. If cancer is a disease state then the sufferer, without treatment, must be experiencing or going to experience a deterioration of capacity to function. But this does not apply to the overdiagnosed.

So, the screen diagnosis would be characterised only as a possible non-cancer or false positive for cancer as well as a possible cancer. It would be an indeterminate diagnosis; the relative probabilities for each possibility are not known exactly but are between, according to current best evidence, 30-50% chance of being a false positive (Biller-Andorno, 2014). The diagnosis would not be a mal-detection as Rogers suggests (Rogers & Mintzker, 2016), but a mis-detection, or mis-recognition.

This is important because it would make it less likely that population-based screening would remain acceptable in the court of public opinion, and would add to pressure to re-evaluate and possibly stop cancer screening programmes.

The arbitrary choice of histological cut-off to diagnose cancer is another internal value judgment that is determined by a judgment about how much harmful cancer
Language, harm and overdiagnosis – chapter 4

*should not be* missed, that is, the cut off is a socially necessary or traditional and acceptable level of screening test sensitivity, usually set, if acknowledged, at above 90% (see more on this in chapter 6). And, overdiagnosis by screening is always inevitable because screening technology is not able to specify the representation of the moment of disease genesis and *to know* the future functional progress of screened tissues. In addition, the screen cancer signs are pictorial and visual, and as such they are a qualitative and continuous variable, so whilst they are empirical sense-data, they are not finite, discrete, or measureable and are, therefore, not amenable to statistical determination of normal, or typical, biological or physiological function. For example for diagnoses based on appearances there is always a *visual ambiguity* (Lowy, 2010 pp146-67), and therefore Boorse’s concept of disease (BST), which requires empirical and positivist data, (finite and measureable), always causes, *but does not acknowledge*, a misrecognition of disease at the borderline between the normal and the pathological at the visual, histological, microscopic level.

In mental health, a recent new diagnosis for a specific disease, such as ‘hoarding syndrome’ (Wakefield, 2016), decides that the future behaviour of that individual is pathological because it is beyond a threshold for accepted social norms.

In physical medicine, a so-called borderline diagnosis may be produced by a blood test for diabetes. At the threshold, the diagnosis is said to be diabetes, and the patient is managed as such, but this is at a threshold between false positives and false negatives. The threshold is set to maximise correct, and minimise incorrect, diagnoses, according to cultural norms.³ So, the question arises, can this threshold diagnosis be called real diabetes or not?

Overdiagnosis is a marker of this diagnostic paradox in which failure of diagnosis is inevitable. And, if a screening programme’s diagnosis of cancer fails to accurately predict the future of the individual as becoming symptomatic in some way, then the question arises: is the diagnosis ‘real’ cancer?

So, what might ‘real’ mean in this context?

Let us say this refers to real as in *pathological*, then we can take five possible perspectives of: the etymological, that is, the origin of the word; the pathologist; the
surgeon; the intended screenee (an individual who undergoes screening); and finally
the capitalist marketplace.

The word itself, pathology, implies a *pathos*. That is to say a concrete and direct
feeling of suffering and powerlessness, which implies suffering in the present, and
therefore evokes the sense of a visible or felt threat now, which, in turn, demands a
level of urgency, increasing the desire for treatment.

For the pathologist, convention as opposed to evidence, has encouraged the belief that
certain tissue appearances were an ‘entity that represented a grave danger to the
individual’, and apart from occasional dissent this has become a normative view.

In the early 1900s it was commonly believed by surgeons that irritation or
inflammation was a cause of cancer and many women with cystic breasts, were
diagnosed with chronic inflammation, mastitis, and had them excised in the belief this
would prevent cancer developing. By the 1920s and 1930s pathologists were
increasingly taking over from surgeons the role of confirming whether excised tissues
were cancerous, and by then it was increasingly recognised that mastitis never led to
cancer, and was a glandular cystic problem that did not require excision.

“The irritation theory of carcinogenesis continued to dominate the understanding of
cancer in the inter-war era …” (for a good account of the historical development of
pathological diagnosis see Lowy, 2010 especially pp57-67). This reinforced a belief
that early diagnosis and treatment could prevent cancer deaths. In the 1920s and 30s,
for cystic mastitis, their were ‘a wide range of therapies’, and ‘dissimilar beliefs held
by surgeons and divergent interpretations provided by pathologists (Tod, 1934
p1045). The latter, pathologists, faced a challenging task: to provide a *firm diagnosis*
for a morphological entity with an unclear definition and fuzzy boundaries

The history of diagnosis of such lesions is that of *visual ambiguity*: “Magnification
drives to the centre of the major aesthetic problem faced by all natural history
descriptions. What do you do with beings that are neither one thing nor the other?”
(Stafford, 1996 pp146-67).

Does the pathologic diagnosis signify a predicted outcome and therefore desired
intervention? If yes, then a cancer diagnosis, or pre-cancerous diagnosis, indicates
some kind of intervention even if it is so-called surveillance. ‘Fundamental scientists look for ways to produce order … in visual representations of highly variable manifestations of life … without undue simplification.’ For practitioners, ‘the main problem is to produce an unambivalent knowledge’, and ‘for pathologists’ the main concern is ‘the ethics of medical intervention … they often observe ambivalent images, but their duty is to interpret these images within a coherent analytic framework and to provide a verdict that will guide the clinician’s actions’ (Lowy, 2010 p57 my italics). It seems clear that the appearance signifies that the desired result is treatment. So the ‘real’ in ‘real’ cancer signifies an outcome and guides action, a prediction that tissue will cause problems which is, therefore, sometimes wrong, and a misdiagnosis.

It was the appearance of the cells themselves rather than any evidence of invasion that led to the first diagnoses of ‘carcinoma in situ’, the diagnosis nowadays known to have the most unpredictable outcome, and asymptomatic so found by accident or screening. Some experts argued ca-in-situ is a true (read ‘real’) cancer, whilst others, in 1934, demurred; saying cellular changes alone (that is without invasion) are not a justification for the diagnosis of cancer. But increasingly cellular changes themselves became known as ca-in-situ or precancerous. However a French surgeon Gricouroff held a ‘sceptical view’, he ‘stressed the difficulty of tracing a boundary between normal and malignant tissue’, and came to the conclusion that:

“it is totally impossible to trace an absolute limit between benign and malignant structures”, not only cancer but precancer itself is a conventional classificatory category and not a natural entity’, so in other words, not ‘real” (Gricouroff, G. Bulletin du Cancer 42 (1955) pp97-111, cited in Lowy, 2010 pp 57-83 my italics)

Thus, the pathologist’s work is to provide diagnoses, based on degrees of correlation of appearance to outcome, to guide surgical practice, but an asymptomatic cancer diagnosis is not causing pathos, suffering, now, in the present. Instead, for screened diagnoses, the pathologist’s work, that is, their work of diagnosis symbolises tissue as predicting, and anticipating, pathos in the future.

The surgeon believes the prediction implicit in the diagnosis, and calls the diagnosis a ‘real’ cancer, a ‘real’ pathology, on the basis that the prediction is likely to be correct,
yet it is still not causing pathos. Nonetheless, for the surgeon, intervention is indicated.

For the person offered screening the diagnosis of cancer, named as such in varying ways always feels ‘real’ – that is, a material threat to life, and conjures up individual beliefs about cancer as ‘a potent driver of thought and action because it incurs fear’ (Lowy, 2010 p103) that ‘often invokes the spectre of an inexorably lethal process’ (Dunn, 2013 editorial). If it is not causing pathos, and never will cause pathos, that is to say, it is an overdiagnosis, or a false positive, then should the word ‘real’ be applied to the named apparent pathology? After all, the pathologist’s prediction is mistaken, the surgeon’s faith in the prediction is mistaken, and the person screened is frightened unnecessarily.

Many of the cancer diagnoses by screening, and the subsequent tissue biopsies examined under the microscope, are at the threshold for the specificity of disease, that is, there is real uncertainty about the future biological future of that tissue. But pro-screening advocates gloss over this uncertainty.

The scientists who are employed as experts by political powers often function as part of institutional powers that shape social norms in terms of scientific justification for social practices and could be called scientist-politicians. I provided examples in chapter 3 of scientist-politicians in the membership of the UK breast cancer screening review panel chaired by Professor Marmot, and by the so-called UK cancer Tsar Prof. Richards interviewed on the radio to promote screening. Such scientist-politicians promote normative social behaviours and market screening using language to counter uncertainty. Their language is consistent with a neoliberal, radical empiricist, pragmatism when they claim that all screen diagnoses are ‘real’ cancer. In other words, first, it is only their impression of the effects of screening on cancer deaths that counts. And, second, their impressions do not take into account whether a screen-diagnosed cancer would ever actually cause symptoms or future harm.

**The real cancer paradox**

I suggest that the diagnosis is named as ‘real’ cancer to validate the diagnosis as accurate, a discursive act that functions to sustain medicine’s authority, and to win over public opinion. This rhetorical manoeuvre maintains public faith in the screening
process. Medical experts’ elite and subjective impression may well be that the histological appearances do give a true representation of the dynamics of the tissue physiology and its cancerous, that is, its uncontrollably growing and relentlessly invasive, nature. But, in any case, such an impression is shown to be false by the fact that some such tissues actually regress and fail to ever progress or cause harm.

The pro-screening advocates claim, from the chief executive of a cancer charity: ‘overdiagnosis is different, … it is not a mis-diagnosis … because these women have correctly had cancer diagnosed but it is thought that if left alone this cancer will not cause harm or need to be treated’ (Askew, 2012 my italics).

But, at the threshold for the specificity of disease, at the borderline, the contradiction remains, that is, what looks correct now will later turn out to be wrong.

Trading one mode of dying for another

As I have already noted, there is no evidence that breast cancer screening reduces overall mortality rates in the screened population, that is, the rate of deaths from all-causes including breast cancer. The direct implication of this is that screening itself, if it does reduce breast cancer deaths, is possibly, at the same time, increasing deaths due to other causes.

Also note: it is perfectly possible that a breast cancer death may be considered preferable, by some, to other modes of death, such as dementia. In other words it isn’t self-evident that a cancer death is the worst possible mode of death. As Richard Smith one time editor of the British Medical Journal wrote, reflecting on the thoughts of the Spanish film director Buñuel about his own and Franco’s very different deaths:

‘The long, slow death from dementia may be the most awful as you are slowly erased, but then again when death comes it may be just a light kiss … so death from cancer is the best, the closest to the death that Buñuel wanted and had. You can say goodbye, reflect on your life, leave last messages, perhaps visit special places for a last time, listen to favourite pieces of music, read loved poems, and prepare, according to your beliefs, to meet your maker or enjoy eternal oblivion.’ (Smith, 2014 p1).

Death from organ failure—respiratory, cardiac, or kidney—may have you far too much in hospital and in the hands of doctors.
To summarise then, the pressures of neoliberal pragmatist empirical positivism, that is, the market and radical empiricism (described in Chapter 2) are the real basis for the practice of healthcare. But this truth is masked by the fantasy, of EBM and EBHC, that an objective logical empiricism guides practice that can be consumed by apparently free thinking autonomous individuals.

Persuasive rhetoric, that this mode of care ‘works’ and ‘should continue’, sells this mode of care to practitioners by ensuring that the threshold for disease supports intervention, by, for example, naming it as: always a case of real cancer. The persuasive rhetoric also claims that because overdiagnosis is a known number, then individuals have a clear choice and can make a fair decision.

Whereas, although overdiagnosis causes real harm due to completely non-beneficial mastectomies, the fact and number of overdiagnosis is also, as knowledge, meaningless, or devalued as harm at an individual level, because it is never personally experience-able, or imaginable, as such.

Therefore overdiagnosis can never be taken into account in a fair decision, fair in the sense that the harmful potential consequences are felt and weighed up realistically and meaningfully, *as if* this is a democratic process.

Thus, both the terms real cancer and overdiagnosis function to make certain possible meanings impossible or *unconscious*. In a sense they function, through the expert rhetoric, to fix meaning and to indicate the social role an individual should adopt in relation to screening. This has important implications for subjectivity, how the individual attempts (but always fails) to secure an identity through the perception of her self and her role, an issue taken up in later chapters.

Therefore, this anticipatory mode of care is necessarily anti-democratic. It oppresses subjectivity with illusory discourses that impose care. This is a process that is always intensifying under capitalism’s imperative for competition. And this, in part, helps to explain the paradox by which anticipatory care is increasing and is, at the same time, increasing harms.

One possible response to this would be to argue that whilst healthcare providers are also subjects of a capitalist society, and, as such, as prone to market pressures as
anyone, it is still possible for them to witness practice and to reason about the effects of anticipatory care as oppressive. Health care providers could wield expert power to argue that anticipatory care such as population based screening should not be offered in some, perhaps most, circumstances in wealthy, albeit socially unequal, societies. This raises other issues that are developed in later chapters, and I won’t extend this discussion here. However, one thorny issue for which I don’t have an answer, for example, is that even though the overdiagnosed are oppressed they tend to feel they are not, and conversely often over estimate the benefits and believe that they have actually benefited from screening, so it would be difficult to practise any kind of non-supremacist liberating resistance to oppression in partnership with the already oppressed.

The fantasy that objective logical empiricism is the basis for guiding care practice and that EBM provides objective and democratic evidence for best practice, masks a neoliberal pragmatist governmentality that is subjective and always intensifies anticipatory care.

I have shown how language is used to have powerful effect on beliefs, and, therefore, on behaviour. Neither EBM’s logical, nor pragmatism’s radical, empiricism can adequately explain how rhetoric exercises this power. This raises questions: why, and how, is neoliberal pragmatism able to wield such power over public opinion, and to continue expanding care technologies that are causing increasing harm? I begin to address these questions in the next chapter, through Marx’s idea of commodity fetishism.

NOTES

1 The review also emphasises benefits in favour of harm by failing to quantify the small chance of benefit in its conclusion whilst quantifying overdiagnosis: ‘... the choice is clear ... screening confers a reduction in the risk of mortality from breast cancer because of early detection and treatment ...’ (Policy Recommendations, Marmot, 2012p1784). The review neglects to say that by its figures a woman screened from the age of 50, every three years, over twenty years has perhaps a 0.4% chance of having a breast cancer death prevented, but does goes on to say: ‘she has ‘perhaps a 1% chance’ of being overdiagnosed. The chances of other, imaginable, foreseeable and quantifiable harms are not mentioned, except the chance of death due to side effects of mammography, which is described as ‘minimal’.
In 2013, authors from the National Institute of Cancer in the USA wrote an editorial: “The word cancer: how language can corrupt thought” (Dunn, 2013 editorial). The mere ‘labeling of ... lesions as ‘cancer’ or ‘carcinoma in situ’ is a ‘potent driver of thought and action because it incurs fear’ (ibid.), ‘... the word (cancer) retains its fearsome quality sometimes corrupting thought and action’. And, a 2012 US National Cancer Institute convention stated: ‘the word cancer often invokes the specter of an inexorably lethal process’ (Esserman et al., 2013p797).

Thus, the name, or signifier cancer already incites fear and urgency of action. To call it ‘real’ cancer signifies threat that needs to be averted somehow, it incites fear and a need to anticipate the danger by accepting treatment, it makes sure fear and urgency are retained.

Anticipatory Evidence Based Diagnostics

This threshold between false positives and false negatives is what is at stake in diagnostic Evidence Based Medicine. The science of logical empiricism (or logical positivism) relies upon observable measurable finite outcomes. This in turn requires an understanding of the ‘performance’ of diagnostic tests, such as those used in cancer screening. Screening diagnostic tests always come up against the impossible to specify point of difference between the normal and the abnormal. Therefore, I argue that one of the particular features of screening diagnostic tests is that there is no gold standard, as it is called, by which the test’s accuracy can be judged, that is, by which a given result can be validated as definitely true or false. (Note however, that it is traditionally argued (see for example Rogers & Mintzker, 2016) that there is a diagnostic gold standard, defined as the ‘best available’ test, but I argue this is disingenuous as the ‘gold’ implies more than ‘best available, it implies certainty). The screening test, then, must always be inaccurate at the point of attempting to specify abnormality. And so, having decided to do the test in the first place, a necessary question then becomes: What must be done with the result, and the patient? What is to be done depends, crucially, on exactly where the line is drawn between the normal and the abnormal, or pathological? This problem is addressed by (mathematically based) theories of evidence based diagnostic testing and many hours of educational resources for practitioners are devoted to this (Newman & Kohn, 2009).

The thresholds for diagnostic tests are artificially refined, using what are in effect socially accepted conventions, to ensure that a certain minimum proportion of actual cases will be found by the test. This minimum proportion of actual cases to be found is called its sensitivity. However, because of its inbuilt inaccuracy, the more the threshold is shifted to ensure greater numbers of cases are detected, that is, greater sensitivity (to provide benefit for those who might suffer), then the greater the number of innocent, non-cases, are caught in the net and the number of what are called false positive results increases (causing harm to non-sufferers of the disease in question).

This can be represented graphically by a receiver operating curve (ROC), where each point on the curve represents a different threshold, that in reality is chosen to ensure either a certain minimum sensitivity, increased if the disease is deemed to be serious, or a certain
minimum specificity (that is, the lowest number of false positives), increased if the disease consequences are less serious.

![ROC Curve](http://www.medcalc.org/manual/roc-curves.php)

On this graph each point along the solid line would represent a different threshold, chosen by the clinician or scientist. It is clear then that for such tests, the threshold remains a balancing act between two lies: false positives and false negatives. The dotted line is an imaginary useless test where the result neither predicts normality nor abnormality one way or the other, both are equally likely. The closer the curve is to the y axis the more useful the test.
Politics and consciousness

Introduction

This chapter uses Karl Marx’s analyses of labour-power and commodity fetishism to illustrate that consciousness, in the form of beliefs, is shaped, not only by taken for granted cultural norms, but also by capitalism itself (Marx, 1976).

In this chapter I argue that capitalism is able to cause an alienation of knowledge from beliefs because human consciousness is never fully self-aware. I argue that this makes individuals susceptible to: a) normative cultural beliefs (for example, early diagnosis by screening is a good thing); b) an excessive desire for health technology (screening tests are a desirable thing); and c) harm caused by anticipatory care because the meaning of known harm is made ungraspable as meaning harm as such, and is therefore unconscious.

In this chapter I use Marx’s analysis of alienation, labour-power and commodity fetishism, this analysis is shown in later chapters to use the concept of unconscious meaning as derived from Lacan’s psychoanalytic theory of subjectivity and alienation.

Here, I explain the relationship between Marx’s theory of labour power and Lacan’s ideas of subjectivity through alienation, and how their theories of labour power and subjectivity, respectively, can be combined.

Note that I do not explicitly use, or explore further, Marx’s idea of the alienation of estranged labour here, although this is an important idea for thinking about how the forces of capitalism subjugate and objectivise the human, and the way capitalism destroys social bonds.

At the same time, whilst Marx sees the labourer as alienated from his outputs and fellow workers, he also saw the productive and dialectical relation between work itself and consciousness; for example:
‘He sets in motion the natural forces which belong to his own body, … in order to appropriate the materials of nature in a form adapted to his own needs. Through this movement he acts upon external nature and changes it and in this way he simultaneously changes his own nature’ (Marx, 1976 p283).

This is a dialectic promising the optimistic possibilities of change in us and of our potential action upon the world. However, the origin of the particular processes, with their particular exploitative, subjectivising effects on consciousness affecting us all today, lies in the social relations of capitalism. It is these processes and their subjectivising effects that I emphasise here when making use of the analogy between the ideas of Marx and Lacan.

In this chapter, I am beginning a process that develops Lacan’s ideas about identity formation or subjectivity that continues in following chapters. I draw together and combine two structures that are economic, that is, that are held together through relations of reward and production: the social capitalist structures described by Marx’s theory of labour-power, and the personal psychic structures described by Lacan’s ideas about subjectivity.

The psychic structure of the individual is also, by analogy, economic, and as with Marx’s quote above, the individual’s psychic, or mental/emotional, labour also ‘simultaneously changes his own nature’.

For the individual there are two kinds of reward in exchange for two kinds of labour.

Potential reward take two forms: a) emotional stability, or security, through identity formation; and b) apparent added value to life itself; for example by the promise of longer, surplus, life, through a disease avoided. But notice that the individual, once tested and a decision made about treatment has no sure way of really knowing if she has been harmed or benefited, regardless of what she may believe. This represents an unknowable sliding scale and represents alienation of the individual from the product of her labour/consumption. For example, the process may provide zero use-value (benefit) to the individual’s life if she is overdiagnosed, even whilst the product of her labour may be destruction/mutilation of her body (for example, mastectomy) and economic profits for those selling the process.
Labour takes two forms as well: a) the ongoing psychic work, or cognitive processing, that constitutes subjectivity; and b) the material work in handing over parts of the body for testing, and in consuming the test, and in an uncertain and unknowable balance between destruction and enhancement of capacity to function. The psychic work, cognitive processing, (determined by effective truths, and without individual agency), constitutes an attempt to form subjectivity for the individual, but also provides, along with the body, a consumer of tests, results, and treatments that still desires even more testing. This produces test and treatment consumption that provides profits (surplus economic and semantic value) for those with professional and/or financial interests in the test process.

I argue that there is a strong analogy between Marx’s structure for the exploitation of labour-power in capitalism and Lacan’s structure of the psyche in capitalism. I call this an analogy, rather than homology, because I argue these structures have different origins. For Marx, I suggest, the origin lies in the way social relations produce consciousness (notwithstanding Marx’s acknowledgement that ‘by setting in motion the natural forces which belong to his own body’ the subject can also ‘change his own nature’ as noted above). Whereas, for Lacan, I suggest, the origin of the formation of subjectivity lies in the individual’s original inability to make sense of the self by reference to the self alone, and therefore his or her always-insufficient self-consciousness, or lack of full self-awareness.

Using Marx’s analysis of capitalism, I describe how, through anticipatory care, both the raw material of the body and the consciousness of care labour are put to work, and how they contribute to a form of subjectivity.

**Scientific-political-economic philosophy**

To remind the reader: in the last chapter the relationship between science and politics was examined, but neither could be disentangled completely from the other. The conclusion of the elite expert review of the UK breast cancer screening programme, that it ‘saves lives’ and should continue, shows how public acceptability is shaped by elite beliefs and rhetoric that a) overvalues intended effects of care interventions, and b) masks and devalues unintended collateral harms.
This approach to implementing care is consistent with an overlap between a scientific-political philosophy, of radical empiricist pragmatism, and a political-economic philosophy of pragmatist neoliberalism.

The science is positivist, and the political method for implementing the science is pragmatist. This ensures that science only values, as knowledge, positivist data (the clearly seen, finite and measurable). Politics values, as legislatively relevant knowledge, only elite, expert, impressions that actions have achieved their intended effects (such as breast cancer death reduction).

Positivist science does not value abstractions, and pragmatist politics does not value collateral damage such as predictable side effects, but does value elite opinion, thought and impression, as if it is positivist data.

The dominant contemporary political-economic philosophy is capitalist neoliberalism. Capitalism, described in more detail in this chapter, can only persist and survive as long as there is economic growth through increasing productivity. Neoliberalism reinforces pragmatist philosophy that only values intended benefits for individual interests, and doesn’t value collective welfare.

This complex of science, politics and economics can be described as neoliberal radical empirical pragmatism. It favours, inter-alia, the politically sanctioned marketisation and implementation of ever-increasing forms of innovative anticipatory care.

**Alienation and commodity fetishism**

I use the term *alienation* to refer to the way, for an individual, that is, subjectively, ideas that have conscious meaning are separated from ideas that become non-meaningful, or ungraspable in meaning, so that they become unconscious.

Briefly, capitalism alienates consciousness in two ways: by shaping and reinforcing a) the worker’s conscious belief in her freedom, or her sense of control over her destiny, even whilst she is unaware that she has no choice but to sell her labour; and b) the capitalist’s conscious belief of the capitalist’s autonomous agency as a wealth creator, even whilst functioning as a cog in capitalism’s wealth creating machine.
This alienating process is a function of capitalism. It is described in more detail below. I want to emphasise that it is a central concept for understanding the paradox of anticipatory care, and yet, as an idea, is itself alien to the two dominant philosophical doctrines that control the way care practice is both taught and delivered.

These doctrines are a) *scientific positivism* as the only source of meaningful evidence to guide future practice; and b) *humanist pragmatism*, the idea of human subjectivity as a fully self-aware and self-creating agent, whose collectively ‘agreed’ thoughts are also positivist, reliable, clearly seen evidence, and sufficient to guide future practice.

For students of psychology, in particular, note that these ideas are also the basis on which the interchangeable ‘mind’ is regarded as a reliable object of scientific positivism, as if science can explain the mind, an approach which reinforces capitalist alienation and exploitation. This has been described as the *psychologisation* of the individual (Parker, 2015a p58):

‘By psychologisation I mean the reduction of social processes to the level of the individual subject (*the individual mind is sufficient to guide social practices*) and the induction of that subject into an understanding of themselves in which psychological explanations take precedence (*the construction of a belief*). That psychologisation commences with the birth of capitalism is in fact a necessary condition for capitalism based on commodity exchange to work. Not only does each worker enter into the contract to exchange their labour time for money as if it were of their own free will, but the entrepreneurial activities of the capitalist provide a model for thriving competitive individualism that seeks to maximise profit. Psychologisation is necessary through the development of capitalism as the material ideological texture of everyday life (*the taken for granted, as if natural, way*), through which economic mechanisms appear to be grounded in survival of the fittest, and it has become all the more important in times of neoliberal deregulation of welfare services and intensification of precarious entrepreneurial labour conditions (*including care labour*), in which the worker is now also an entrepreneur’ (Parker, 2015a pp57-8 my additions in brackets)
I use the term *commodity fetishism* to refer to belief in the somehow mystical and apparent power of commodities to self-generate or self-actualise greater wealth and life enhancement. It is partly this belief, or fetishism, that evokes a sense of, or reveals lack and so incites the desire to consume.

Thus, commodity fetishism is the power of the objects offered for sale to *apparently* create a) ever more economic wealth, b) the illusory lure of ever more sense of self and purpose, and even c) ever more life itself. And this power exists in reality because, magically, the commodity seems to be able to do this simply by being a commodity, and is responsible for belief in this power that decides concrete behaviours. There is no sign that the surplus generated requires any work or effort, it simply requires employment, exchange and consumption. This is because its source, the exploitation of waged labour, is invisible, hidden in the workplace: the sphere of production.

Alienation under capitalism is the key process by which humans are induced to hand over their agency, or freedom, to the oppressive control of others, in the mistaken belief that this is the only, and natural, way to achieve a greater freedom.

Most simply put, this separation enables the source of profit, that is, the exploitation of waged labour during production, to remain hidden (and therefore, unconscious) from the visible (and therefore conscious) view of the open market.

**Agency and decision-making**

I want to emphasise the relevance of Marx’s ideas of alienation and commodity fetishism to the practice of healthcare.

Briefly, to remind the reader, as noted in chapter 3, expert spokesmen claim that the fairness of the breast cancer-screening programme is a good thing because ‘we now have a number’ for overdiagnosis, 4000 per year in the UK, and so patients can now be told about the ‘pros and cons’ ‘in a balanced way’ (BBC, 2012b).

Thus, the public acceptability of screening is assumed and based on knowing and providing ‘a number’ for harm, that is, a quantity of a harm of a known nature. It is implied that, once this knowledge is imparted to the patient, the ball is in the patient’s
park: it is up to them to make their own decision, or as is often said, the ‘right’ decision for them.

The rhetoric of the fairness of, for example, patients making decisions about cancer screening, is based upon underlying assumptions about agency and consciousness. The assumption is that individuals have complete agency, that is, are fully self-aware and ‘free’ to make decisions as free agents in control of their own destiny.

Marx’s analyses of alienation and commodity fetishism challenge this assumption of individual freedom and autonomy by showing that individual’s beliefs are shaped by capitalism in a way that reinforces this false sense of freedom or agency.

**Anticipatory care, agency, alienation and commodity fetishism**

An example from healthcare will introduce and make Marx’s terminology and abstract ideas more useful, and help to transfer them into terms applicable to anticipatory care.

So, for example, even the knowledge in a test result produced by any screening test functions as a kind of commodity available for exchange in a market. The individual offered the test might feel free to accept such an offer, as if she has full agency. However, she is in fact incited, by fear, to accept the offer by the rhetoric of, say, ‘saving lives from cancer’ as if this is a matter essential to her personal future wellbeing, or even survival.

The test result is both a) a product produced by the patient from the raw material of her body, as well as b) a commodity exchanged – when the professional carer imparts the result to the patient. Thus, within the one individual there is a sequential development in her role as first a) clinical or care labour, producing the commodity, the test result, and then, second, b) as care consumer, ‘buying’ the result from the carer.

*As care labour*, the offer incites the individual to feel a need to offer up her body, or ‘sell’ her labour power, in the form of a sample for testing, with the expectation that her ‘wages’ will be her future increased chance of survival. Her labour power as patient-being-tested is exchanged in a kind of employment market. Despite appearances, she is not ‘free’ to do this, because she is being incited by fear and is
under duress, and if she agrees, her body has become, for a time, the effective property, and raw material, of the screening programme.

As *care consumer* she ‘buys’ the test result, by exchanging it for a decision about treatment, decisions that, on the whole, end up in a decision to act and comply and to be treated, or re-tested. It is as if the test result speaks through the patient to the next commodity in a chain, perhaps the treatment, or perhaps to another test. The patient becomes an exchangeable cog in a machine, a cog that simply facilitates transfer of the effects of care commodities from one test to the next, and so on.

This anticipatory care process is alienating, that is, one idea is made conscious and forms a conscious belief, whilst another idea may be known, but is nonetheless made unconscious and, thereby, not believable. Thus, the offer of the test alienates her from her sense of self as healthy by introducing the idea of her hidden cancer. This idea of a hidden cancer then leads to a conscious belief in the possibility of her cancer and in her need to be tested, and this makes unconscious the idea of herself as healthy because she has no symptoms.

In Marxian terms, as Tomšič puts it, the subject is: ‘… understood not as an autonomous consciousness but as a real consequence of the autonomous signifier’ (Tomšič, 2015 p54); here the autonomous signifier is the screen-diagnostic test and its associated screen-cancer diagnosis, and we can see that ‘… the human essence is no abstraction inherent in each single individual. In its reality it is the ensemble of the social relations’ (Marx, 1968 p VI, p2).

**Marx’s theory of labour power, alienation and commodity fetishism**

Marx’s analysis illustrates the way that human subjectivity is never fully self-aware and so complete freedom or agency is never possible, even whilst capitalism (and neoliberal pragmatism) promotes the illusion of agency in ways that sustain oppression.

Marx analysed the capitalist system in *Capital* vol. 1 published in 1867 (Marx, 1976). Perhaps the most important aspect of capitalism is the separation of the workers from the ownership of the means of production. This means, most simply, that workers no
longer have direct access to the means of survival other than through being employed, for more or less adequate wages, by those that do own the means of production, the capitalists.

For healthcare, the means of survival is commonly understood to include the care of present day suffering, as well as the care of anticipated future ill health. And, so, the production, consumption and access to care is felt to be both essential but a) modulated, for many, because it is dependent on the systems that employ workers to provide care within budget constraints; and also, paradoxically, b) expanded by systems that automatically multiply forms of care, for a few, in the search for economic growth.

Ownership of the means of production

Over time, a process accelerated from the sixteenth century, there has been a gradual and increasing separation (expropriation) of most individuals from the ownership of the means of production. Marx referred to this as the issue of ‘primitive accumulation’ (ibid. p876).

Classical neoliberal economics argues that if the market is allowed to operate free from political interference this will generate wealth that will ‘trickle down’ to the masses. Faith in Adam Smith’s ‘invisible hand’ will ensure social progress and prosperity for all, even whilst it is judged that socio-economic inequalities are quite natural and just. The individual, according to a classical liberal and then neoliberal philosophy, really is free to make it to the top, it’s just that some are, only naturally, more capable than others.

Marx describes how, over time, the process of separation of the labourer from ownership of the means of production is reflected in two parallel processes.

First, there has been an increasing division of labour into ever more exclusive specialisms, beginning with ‘the simple separation of workers into skilled and unskilled’ (ibid. pp468-9). This means that individuals have become increasingly dependent on the skills and knowledge of others to provide for their needs. This is another form of alienation, and it helps to drive a process that has centralised mass labour in urban factories owned by a few.
Second, many of the skills of labourers have been taken over by machines, and the machines themselves have increased the productivity of labour, requiring fewer labourers for the same output (ibid. p545).

Today we can see the same processes still at work in the wealthier capitalist countries, through increasing reliance on technology, and increasing unemployment, and in the poorer third world in the exploitation of raw materials and cheap labour in factories (ibid. p574).

In healthcare, for example, the human being is increasingly alienated from understanding the technology used: for example, the digital algorithms to reconstruct genetic codes to generate personal risk measurements for future disease based on genomic signatures.

At the same time as the separation of the labourer from the ownership of the means of production, the most far-reaching changes have been: a) the resultant employment of labour for wages; b) the development of the illusion that money can just naturally, spontaneously, increase in value; and c) the widespread belief that wealth creation, for its own sake, is desirable, natural and just.

I will describe Marx’s theory of capitalism as taking place in three stages, an employment exchange, a production phase and a product exchange.

**The employment exchange**

First, consider the employment market. When an individual is employed for labour, a few things happen.

First, in the employment market the individual has to get a job to survive, but, legally, is deemed free to sell his or her labour as an equal partner in a transaction with the employer: ‘They contract as free persons who are equal before the law … equality because each enters into relation with the other, as with a simple owner of commodities, and they exchange equivalent for equivalent’ (ibid. p280).

What is exchanged is potential labour power and wages, and the exchange is equivalent in the sense that is ‘freely’ done and legally justified. But, this freedom is
only an appearance, an illusion. It covers up the fact that the individual worker has to sell her labour simply to survive.¹

Under neoliberal pragmatism, the anticipatory healthcare market is being flooded by new technologies and, hence, demands for more care labour. And, this all takes place in the anticipatory care version of the employment exchange, wherever the offer of care is made. The fear, and the inability to conceive of the meaning of overdiagnosis as harm, makes the value of the promised potential cure (the equivalent to the wages) outweigh the price of even predictable and actual harms.

Briefly, there are conventions, or traditionally moral values, that determine how society should accept the relative values for the benefits and harms of care.²

One example is provided by the way socially agreed limits decide the performance of a cancer test. The choice of limit, as I show in chapter 6, tends to be dominated by the test’s so-called sensitivity where, in general, this is set so that it should be at least 90% (that is, so that only 10% of cancers might be missed) (Van ’T Veer et al., 2002 p533).

The specificity, that is, the numbers falsely diagnosed with cancer, is given lesser relative value and lesser importance. False positive diagnosis is regarded as ‘a necessary sacrifice’, but is, in fact, a convention and as such a socially necessary life sacrificed.

As with the wage in the employment exchange, as the negotiable value of labour power, the wages provided by anticipatory care labour is a balance between benefits and harms at a level set by convention to favour intervention rather than non-intervention. The balance between benefits and harms for anticipatory care labour is equivalent to the waged labourer’s ‘necessary requirements … and depends on the habits and expectations with which, the class of free workers has been formed’ (Marx, 1976 p275).

**Production phase**

During the production phase the employer is able to make surplus value or profits. This is because labour power potential is the unique commodity in the human because it is able to create commodities with greater value than that of the labour power potential, because wages have less value than the value of labour expended: ‘By
incorporating living labour into … lifeless objectivity, the capitalist simultaneously transforms value, i.e. past labour in its objectified and lifeless form into capital, value which can perform its own valorisation process …’ (ibid. p302).

Put most simply, employing waged labour in the production of commodities is profitable because the saleable value of the product is greater than the employer’s costs in wages and other expenses.

Once bought in employment exchange, the employer now owns the labour power; in effect the worker’s body and mind have been sold as labour power. So, during the production phase her life is no longer her own.

Vanheule describes how, in the production phase, the worker becomes labour power:

‘In the market the capitalist buys labor power in order to produce merchandise. Marx states that the trick put into practice in this process is that the capitalist pays the laborer as much as he has to, but less than the market value of what the laborer actually produced. In other words, in the process of exchanging value (labor power/money) the capitalist pockets a monetary surplus behind the back of the laborer, and behaves as if he too worked hard during the process of production. Here Marx states that the capitalist must hide his smile: ‘after a hearty laugh, he re-assumes his usual mien.’ This laughter results from the fact that the value that is created during a workday is actually much higher than what the capitalist pays the laborer’ (Vanheule, 2017 p4).

I described the features of care labour above: in anticipatory care this is in the material form of: a) providing a bodily sample for testing, or having a screening x-ray, with her ‘wages’ (security of life) being set to maximise cancer detection and her hope that any future increased chance of survival will outweigh the harms; whilst b) simultaneously producing, and being constituted as, a desiring and consuming subjectivity, (with its reward in at least the anticipated restoration of and/or increase in security of identity).
Product exchange

In product exchange, the employer hopes to sell the product and make a profit. From the perspective of the employer (or the owner of the means of production) it appears as if the selling of a commodity creates effortless extra wealth. The consumer buys a commodity that has, as part of its value, what Marx calls ‘congealed labour power’ – so that the consumer has, inadvertently, also become an indirect employer of labour.

Once on the market, products are then bought and sold. And, it appears as if the money she has in her pocket transforms itself into a larger amount of money simply through exchange.

Marx’s formula for this is \( M-C-M^\uparrow \), where \( M \) is the money used to pay for a commodity, \( C \), and \( M^\uparrow \) is the money received when the commodity is sold. To the employer, or ‘the possessor of money’ who ‘becomes a capitalist’ (Marx, 1976 p235) it appears that value is self-valorising, and forms the potent belief that any commodity has a magical power to increase in value all by itself. This is the meaning of commodity fetishism. Because of this the commodity becomes desired in excess of any use it may have: ‘The capitalist doesn’t actually care about which or what kind of use-value gets produced … as long as it permits the capitalist to procure the surplus value’ (Harvey, 2010 p89).

The consumer and the employing capitalist are both now, in effect, mesmerised by this power of the commodity to apparently self-generate, or self-actualise, more value, as if out of thin air. At this very point, the consumer feels that she does not have enough wealth, and desires to accumulate more.

Commodity fetishism also applies to anticipatory care commodities. And, it seems that the more sophisticated, and newer, the technology then the more it is desired, or fetishised. Thus, the excessive desire for the newest technology through personalised genetic signatures has been referred to as ‘molecular snobbery’ (Baum, 2015).

In healthcare terms, the wealth created is not economic monetary wealth, but, in general terms, has life enhancing value. Neoliberal pragmatist political-economic philosophy emphasises action that benefits the individual self. Liberalism praises the potential of each individual to invest in her own human capital to create an income
stream, and, for care, some of this income stream may be in terms of apparently enhanced life itself.³

**Innovation and the anticipatory care paradox**

The power of the commodity to apparently self-generate, or self-actualise, more value, as if out of thin air, mesmerises the capitalist who is incited to feel not wealthy enough and to endlessly strive to create wealth, that is, further growth in profits.⁴

The net effect of this is inevitable competition and the need for innovation – the demand for new products, of greater desirability to maintain a market share and/or to increase the price.⁵

And, the increasing harms of anticipatory care are made publicly acceptable, in part because of persuasive rhetoric, and in part due to capitalism’s capacity to alienate, psychologise and induce commodity fetishism. This, in turn, is publicly acceptable, and possible, despite oppressing, and objectivising individuals.

The human being is susceptible to capitalist ideology and its inherent illusory fantasies because those fantasies promise desired security and reassurance. And, these fantasies are induced beliefs that create an *apparent* sense: a) of self or identity, b) of freedom or agency, and c) of meaning for a given life within the capitalist culture and its accepted norms for power relations and behaviours.⁶

For healthcare, in general, care practices under capitalism function through a kind of commodity exchange, and thus, through forms of subjectivity. These forms of subjectivity intensify the individual’s repetitive search for a) enhanced wealth (surplus economic value); b) enhanced life performance (surplus life value); and c) enhanced meaning for an individual life (surplus semantic value).

These surplus values symbolise the elusive truths that we chase and believe can be found in the *next* commodity, be it a diagnosis, anticipated disease, or a therapeutic breakthrough. This is belief in the commodity as the solution to our malcontent, whilst we actually know it never will be. Each failed attempt to obtain this truth in the next object of desire reinforces our sense of inadequacy, and makes the feeling of something lost, and the desire for more, even stronger. Thus, whilst there is an individual psychic alienation that alienates the individual from knowledge of her
desire as based on fantasy and ideologically constituted, at the same time she is constituted as feeling free to choose to consume as if this is her meaningful purpose in life. This belief separated from knowledge, which is disavowed, is a basis for many social norms, customs and superstitions which whilst known to be based in fantasy, all the same have the power to capture us emotionally (see Mannoni, 1969 for a classic text).

This is part way to understanding the anticipatory care paradox but it fails to address the wider destructive social consequences of increasing anticipatory care. This is explored in chapter eight on the way regulatory bodies police care innovations in social environments with budget ceilings. It also fails to address why human subjectivity, and consciousness, is never fully self-aware. And, in later chapters I draw from Lacan’s psychoanalytic ideas to take this question further.

NOTES

1 There is bias in favour of the owners of the means of production in the struggle over wages. This bias is publicly, and therefore politically, acceptable because a) the process is perceived as natural rather than man-made, b) it is based on the law, and c) it is those with an interest in the interests of the capitalists, on the whole, who make the laws.

The bias also persists because, after all, the labourer has little or no choice but to accept if she is to survive, and she knows that if she refuses a wage because it is too low, because of increasing unemployment, or the import of cheaper labour from poorer countries, there is always somebody else to take the job.

2 For anticipatory care we can see that culture fixes particular values for the different kinds of outcomes for care. These values are fixed so that they differentiate between outcomes, and these differential relations determine the nature of care provided.

For example, an outcome, say, saving lives from cancer deaths, has value or meaning fixed to it relative to values or meaning fixed to the harms caused in the process of saving lives, such as pain inflicted, wound complications, later effects on relationsips, or mental health. The relative values of these meanings are accepted, and taken for granted, cultural norms, or in Marx’s terms we might say they are socially necessary and set by traditional moral values.

3 By subjectivity I am referring to the way an individual tries (but can never wholly succeed) to make sense of her self and of her social roles. Here, the individual’s subjectivity is dominated as an object by: a) persuasive rhetoric; as well as b) the effects of alienation and
commodity fetishism. And, at the same time, the individual has a role constructed for her as a compliant acting patient. She is meant to feel free, but any agency, or control she may have is being wrested from her. As both care labour, and care consumer, the individual is incited to both a) care for herself, by becoming an object of her own caring, and as her own raw material submitted for testing, as well as b) then caring for herself, with a role as decision maker, incited by the test result to act. This process shows how power functions within anticipatory care.

4 Or, what Marx referred to as ‘relative surplus value’ – the difference between the expenses and the income for the capitalist. So, for example, wages can go up, but at the same time profits can also increase, the costs decrease, because of, for example, increased efficiency of production, cheaper raw materials, better machinery, or fewer workers, or the value of the product increases - perhaps because of, for example, the bankruptcy of a competitor, increasing relative surplus value.

So, any one capitalist will always seeks to increase profit margins, and to stay in business, by increasing efficiency, or by reducing prices to maintain, or take a bigger share of the market. This threatens the profitability of other businesses, which, in turn, seek to be able to stay in business, or to take a bigger share of the market, by reducing prices, or by making more desirable products at a greater price.

In other language, capitalist subjectivity is ‘constituted as alienated’ by a ‘cognitive misperception of commodities’ (Tomšič, 2015 p53) or, a mistaken belief in the power of commodities to self generate more economic value, as if out of thin air. This is the second alienation, the first, ‘constitutive alienation’ (ibid. p53), happened to the worker in employment exchange when her potential labour power was bought by the capitalist. The worker’s misperception is of her agency, or freedom from oppression, and of how it may be maintained.

5 Innovation can occur through finding new ways to stimulate demand, new sources of new raw material, new ways of tapping into raw material, or just new sources of raw material. At a national level imperialist ambitions aim to find new sources of raw materials, today notably sources of energy, such as oil or gas, by seeking to expand territorial boundaries and military occupations. Also, for example, at national level, demand can be stimulated for security interventions by propaganda about national and public security risks: by demonising another nation as a security risk to the home nation (Halper, 2015).

Life itself is also a source of new raw materials, for example by being the tissue tested with innovative technology. For example, new tests can create innovative biological constructs from life by the way genetic signatures are devised by fragmenting the human genome and reconstituting, as a small segment, a signature that can estimate individualised risk of future disease (Miller et al., 2011). As another example, innovative tests can take the form of new diagnoses of mental illness, officially sanctioned through The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association (APA) (Wakefield, 2016).
The way, historically, human subjectivity: consciousness and its beliefs have been constructed, by material social relations (those social relations that form and limit the conditions of possibility for the means of survival) has been described as *historical materialism*.

Historically, capitalism has caused a major shift in the locus of the source of the beliefs for human consciousness. I will briefly foreground this idea here, which follows Kordela’s work (Kordela, 2013a):

In the presecular (or broadly speaking, religious) block of time, that is, before capitalist relations began to emerge around the sixteenth century, the human compensated for a never fully aware self-consciousness with a religious faith in a transcendental (non-earthbound) God or Spirit. But, at the same time, she retained a full awareness of her really lived existing conditions and relations.

This ‘God’, the apparent source of meaning, has today, in our secular (non-religious) and capitalist block of time, instead of being otherworldly, (transcendental) become part of our earthly domain, (immanent), and ‘God’ now takes up a place, on earth, as the potential for enhanced life or greater wealth (potential surplus), to be found in commodity exchange, in a way that makes our individual mortality radically uncertain or unconscious (Kordela, 2013b).
Subjectivity, care-labour and Lacan’s structures of discourse

Introduction

This chapter examines how the anticipatory mode of healthcare functions within discourse structures to create alienating identity for future patients as care-labour.

First, I use Jacques Lacan’s structures of discourse, to show how the capitalist processes of alienation and commodity fetishism relate to the psychodynamic processes that form subjectivity.

Second, I use Lacan’s structures of discourse to show how anticipatory care discourse works to constitute subjectivity and exploit care-labour (patients).

A third aim of this chapter is to introduce Lacan’s ideas about human subjectivity as something always desired and pursued yet never wholly achieved, and as created from an always fragmented or insufficient sense of self or self-consciousness.

Finally, then, I hope to provide an explanation for why neoliberal pragmatism (the political-economic philosophy that uses legitimised scientific-political knowledge) has such a powerful grip on the human psyche, and why, as a result, the anticipatory care paradox continues to be able to increasingly intensify its harms.

To remind the reader, the anticipatory care paradox is the contradiction that is caused by intensifying modes of anticipatory care, in the name of improving health and wellbeing, where, instead, they increasingly harm health and wellbeing.

I use the term subjectivity as the always insufficient sense of self, or identity, that a person strives for but never achieves, feels, and, as if freely, adopts. It is constituted by and through the materiality of speech and language of social normative symbolic discourse and is not the result of self-determination. It provides for an insufficient and always illusory sense of wholeness and completeness of self, and a sense of meaning.
or purpose to life that always has a politically and economically active function. It is not something fixed in time, or kind, for a given individual but is, rather, always in flux, unstable and in need of constant forming, unforming, and reforming along multiple symbolic axes of power.

**Lacan’s structures of discourse**

Lacan’s structures of discourse are a useful theoretical resource for illustrating social relations and functions under capitalism (Lacan, 1991). The discourse structures show how rhetoric, or language (discourse), exercises power through social relations and institutions to form human subjectivities with particular beliefs and social roles.

The underlying Lacanian discourse structure has four quadrants, termed: Truth, Agent, Other and Product (see Fig. 6.1). The arrows represent discourse (language used) exerting power between these quadrants by fixing meaning, or, in other words, what should be understood, consciously believed, and acted upon.

Meaning is fixed, or delineated, where the horizontal bars in the structure indicate a moment of repression in discourse. At these bars meanings are fixed a) as value-able and graspable, by virtue of b) making contradictory meanings no longer graspable as meaningful. This will become easier to understand when I apply it to an example from cancer screening.

I will focus on the role of Agent, in the top left quadrant, as the place from which the structure is set up. This structure is useful because it helps us to illustrate the way an agent functions to set up social relations, within and between individuals and institutions, that provide a basis for the formation of particular subjectivities.

Four different elements can be imposed on top of the underlying structure in Fig.6.1. These always occur in the same order going around the quadrants, but they have different functions according to which particular quadrant is occupied. These elements are identified with the notations: S1, S2, $a$, and $S$, and these have different implications and meanings depending on the structure and their position, see Fig 6.2 (Lacan, 1991).
Fig. 6.1 Lacan’s underlying form for the discourse structure

<table>
<thead>
<tr>
<th>Discourse of the master</th>
<th>Discourse of the university</th>
</tr>
</thead>
<tbody>
<tr>
<td>$S_1$</td>
<td>$S_2$</td>
</tr>
<tr>
<td>$S$</td>
<td>$a$</td>
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<tr>
<td>$S_2$</td>
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<td>$S_1$</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Discourse of the hysteric</th>
<th>Discourse of the analyst</th>
</tr>
</thead>
<tbody>
<tr>
<td>$S$</td>
<td>$a$</td>
</tr>
<tr>
<td>$a$</td>
<td>$S$</td>
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<td>$S_1$</td>
<td>$S_2$</td>
</tr>
<tr>
<td>$S_2$</td>
<td>$S_1$</td>
</tr>
</tbody>
</table>

Fig. 6.2 Lacan’s discourses of the master, hysteric, university and analyst (Lacan, 1978)
These structures are ‘ideal-types’, that is, they are types of an idea, where the idea is that subjectivity, the identities individuals more or less adopt, is always a combination of multiple possibilities forming, unforming and reforming, in flux. They also represent ideal scientific-political-economic categories with social functions, which I hope will become clearer with the examples that follow in the next chapter.

These structures show how, ‘discourse unfolds … when someone forges a position in relation to another’. And discourse ‘unfolds’ and ‘takes shape’ when ‘someone plays the role of the commanding agent’ from the top left position in the basic discourse structure above (ibid. p29).

There are four possible structures. But, here, I will focus on the university structure because this is the structure that is identical with (or homologous to) the structure of contemporary capitalism, and relevant to my analysis of anticipatory care.¹

The university discourse

This is called the university discourse because the place of agent is the place of expert knowledge, S2, the kind that, perhaps, traditionally, universities produce.

In the university structure, U, the agent’s position, A, is top left in the quadrant and occupied by S2: all-knowing expertise. This is the key position that must be filled to set up the structure to begin with, to enable it to become operative as a discourse structure, or what Lacan called a semblance (ibid. p4).

In my example here, the agent, S2, is the expertise that sanctions the screening programme. The agent, S2, via its screening bureaucracy, addresses the other, the anticipated patient, through the ‘offer’ of screening, or a test result, in the top horizontal arrow. This other, the anticipated-patient, is then induced to occupy the position of ‘a’, work, as care-labour, in the university structure.

Note that the university structure is the same as (or is said to be homologous to) the structure of capitalism itself. And, therefore, it provides us with a very useful tool for disentangling the relations between subjectivity, the subject, and the anticipatory mode of care under capitalism.
Lacan’s discourse structures show how, ‘through the instrument of language, a number of stable relations are established, inside which something that is much larger and goes much further than actual utterances can, of course, be inscribed’ (ibid. p13). The university structure is the one that shows the power relations at work under capitalism. I am applying this university structure, which I have slightly simplified, to show power relations for one form of anticipatory care: breast cancer screening.

**Institutional knowledge, persuasive rhetoric and commodity fetishism**

I will illustrate the processes at work in the university structure of discourse with reference to the breast cancer screening programme (see Fig. 6.3). I divide the structure into a left and a right side.

![UNIVERSITY STRUCTURE FOR BREAST CANCER SCREENING](image)

*Fig. 6.3 Lacan’s university discourse structure applied to breast cancer screening*

I use the left hand side of the structure, from S1 to S2, to represent the institutional processes of radical empiricism and neoliberal pragmatism – the scientific/political/economic philosophies that decide what knowledge is legitimised, or warranted, as truth that should guide practice.
The right hand side of the structure in fig. 6.3, from WORK (‘a’) down to PRODUCT (S), I use to represent the anticipated-patient, working as care-labour, and being produced as a care-consumer.

The institutional discourse and knowledge

For the UK breast cancer screening programme, the expert independent review concluded that it ‘saved lives’ and should continue (Marmot, 2012).

The review panel represents S2: all-knowing expertise. S2 knows all that its truth, S1, allows to be known, or what S1 legitimises as knowledge. S2 implements knowledge whose conditions of possibility are both incited and limited by its truth S1.

This elite, powerful agent, S2, is ‘not knowledge of everything (savoir de tout) but is all-knowing (tout-savoir)’ (Lacan, 1971-72 p31). S1, the experts’ truth, intervenes with S2 to fix, or pin, the meaning for S2’s speech in a particular way. The neoliberal pragmatic truth, S1, is, in general, ‘anticipatory care prevents premature death … and is a good thing – regardless of collateral harms’.

At the same time, S2, the expert panel, acknowledged, in terms of their ‘nature and magnitude’, the predictable visible harms, and overdiagnosis. However, I have argued (see chapter 4) that providing information about known harms, and conveying them as a number or scale is not the same as enabling an individual to value-as-harm harms such as overdiagnosis, in terms of them being a personally relevant danger or harm (Marmot, 2012 p1784).

Therefore, now, I can show on the left side of the structure, the first horizontal bar where pragmatism represses, or makes unconscious, the value-as-harm of the harms of screening, and, instead, values-as-benefit only its intended effect, the reduction of breast cancer deaths. This is the first, institutional level of alienation: of expert knowledge of the intended effects of anticipatory care from the source of the creation of these effects: the sacrifice of individuals suffering collateral harms.

S1 is the legitimised knowledge, or truth, of neoliberal pragmatism, and is, in general: ‘early diagnosis prevents premature death (the active intent) and is a good thing’. This ‘truth’ favours the relentless production of innovative anticipatory care interventions to ensure the continued exchange of commodities, such as, for example, by the
ongoing extension to the age range for the UK breast cancer screening programme that *apparently* produces both economic growth and life enhancement (McCartney, 2014; NHS England, 2017a).

The individual’s discourse, care-labour and care-consumer

The right side of the structure represents discourses experienced at the individual level, where ‘a’ represents both the ‘other’ and work, but also as ‘a’ it indicates that the other *never always* (that is, sometimes does not) takes in charge, or always believes, the persuasive rhetoric of expertise, S2.

In the cancer screening example, ‘a’ is work done by the anticipated-patient offered a screening test. This Lacanian discourse structure is analogous to Marx’s analysis of labour power as described in chapter 5. The anticipated-patient is now in the employment exchange, incited by the fear of cancer, and offered work as care-labour, in return for the promise of cancer prevention, and thereby, of enhanced future life. This offer is represented by the horizontal arrow from S2 to ‘a’.

The programme’s institutional expert’s rhetoric about the fairness of the process and the information given encourages the anticipated-patient to ‘feel free’, to make the right decision for her, and to be tested, even whilst she is ‘caused to attend’ screening, and is made to feel her life is in danger because of her presumed, or implied, undiagnosed early cancer.

If she agrees to be tested, her labour power is, in effect, handed over to, and appropriated by, the screening programme. This is alienation with loss of agency, because S2 has decided what her role should be as a compliant patient. Notice that this is *directly analogous* to the worker’s alienation through unconscious loss of agency when she ‘feels free’ to sell her potential labour power in the employment exchange described in the last chapter.

Once she agrees to be tested, and has been tested, she is also committed to being a care-consumer and recipient of her test result. And, she is expected to act on, and according to, the result. If it is negative she should be reassured. If it is positive, that is, it is cancer, then she should accept treatment, which requires consumption as a form of labour.
At the bar on the right, there is another example of alienation through commodity fetishism. There is loss of agency, or repression of meaning. The test result and the treatment decision it decides, appear, like any commodity in exchange, to have the power to self-generate, or self-actualise, not only economic growth, but also life enhancement, and tend to make meaningless, and unconscious the harms of treatment.

For the individual, then, alienation occurs twice, first when the individual loses agency by being ‘caused’ to accept testing by expert rhetoric, and second, when the individual is lured by the test’s promise, purely as commodity offered for exchange, of surplus life: an extension for future life potential. This is the second individual level of alienation.

Thus, it is both commodity fetishism, and the persuasive rhetoric of S2, that makes unconscious, and devalues: loss of agency, limits to individual future life potential, and the harms of treatment, including overdiagnosis.

**The mirror stage and alienating identity**

Alienation, for the individual, refers to the formation of a subjectivity associated with the loss of agency that occurs as a result of the inducement of an illusory belief in truths legitimised by the discourse of a social symbolic order. Notice that discourse isn’t just the language used, say, as persuasive rhetoric, it is also the language used that exerts power by fixing meaning for what becomes legitimised as a social truth. The example I use here is that: ‘early diagnosis of cancer by screening saves lives and is a good thing’.

For anticipatory care, under capitalism, this has been shown to take two forms: a) the way she is made to ‘feel free’ to make the right decision, even whilst she is subjugated, and incited by fear to become the patient who submits herself to its objectivisation by submitting her body to a test, and then to be objectivised, set up as an object of the screening programme, and constituted in her subjectivity as the interchangeable patient who must accept the result of that test and act accordingly; and b) the way she is induced by the effect of commodity fetishism to feel that the technology, and its results, have a magical power to enhance her life beyond its actual capabilities, or use-value.
The question arises: is there something special about the human being that makes her require alienation, as a loss of agency, in order to form a subjectivity that enables her to make sense of her self, of an identity, and social role?

Lacan suggests that the formation of human subjectivity is always through alienation, that is, is always only achieved through an identification with some kind of authority or symbolic order. According to the Lacanian concept of subjectivity (for example see Lacan, 2002b p436), it is impossible for a human to know the self completely or to ever know the world as it really is, in itself. And, according to Lacan there is an ‘insufficiency of consciousness’ that means the human has to go through the mirror stage (Lacan, 2002c).

In the mirror stage the subject is conceptualised as always never fully self-aware. At this stage the infant begins to see, or experience, things that appear to reflect their own behaviours, body and intentions, and not necessarily just their own literally visual image. But these ‘reflections’ never match exactly the child’s direct experience of herself. The child’s sense of self is one of fragmentation and incompleteness.

‘For the total form of his body, by which the subject anticipates the maturation of his power in a mirage … appears to him as the contour of his stature that freezes it and in a symmetry that reverses it, in opposition to the turbulent movements with which the subject feels he animates it.’ (ibid. p95)

**Anticipation and alienation**

The child’s image is reversed, and the image is frozen and appears as a contour of stature, which contrasts with the wildly fluctuating instability of control of movement that is felt by the child. When we look at our image we do freeze it by comparison to how we feel we animate our movements. The mirror, here, is a metaphor for all those mechanisms by which the child is reflected back to itself, as a form of image, by and through others, in touch, expression, sound, language, actions and so on.

‘This development is experienced as a temporal dialectic that decisively projects the individual’s formation into history: the mirror stage is a drama whose internal pressure pushes precipitously from insufficiency to anticipation – and, for the subject caught up in the lure of spatial
identification, turns out fantasies that proceed from a fragmented image of
the body to what I will call an ‘orthopedic’ form of its totality – and to the
finally donned armour of an alienating identity that will mark his entire
mental development with its rigid structure (ibid. p97 my italics).

So, there is both anticipation and alienation, and the child has an unexplained drive to
be whole, to strive for a complete sense of the self. As a social being the child senses
the solution to her fragmentation and expectantly, purposively acts with others
through language and signs, in a symbolic social world. It is through anticipation, and
actions through language, in the social, symbolic world that the child is able to try to
develop a sense of complete self-awareness and identity.

Thus, anticipation is an essential part of the process of forming subjectivity.
Anticipation involves both pleasureable feelings at the prospect of something to be
 gained (such as security from a threat to life), as if it is already possessed, as well as
simultaneously the unpleasureable feeling that this, as if what is not yet possessed
may be lost. The anticipatory mode of care incites a feeling of loss of something and
anticipation of satisfaction through the attainment of the lost object of desire, that
was not there in the first place. Care provides fetishised commodities and this is partly
why anticipatory care is such an effective lure, why the individual so readily takes it
in charge or can be ‘captured’ by it.

The sense of being in some way lacking or alienated from the self persists. And this is
why Lacan refers to a divided subject. Vanheule (2017) suggests that this sense of
incomplete sense of self is the ‘root of jouissance’ (ibid. p4) and is associated with the
‘structurally dysfunctional status that the body has for the human being’ (ibid. p4) and
the permanent sensation of bodily restlessness or libido, that is one of the many ways
Lacan uses the term jouissance. Vanheule (ibid.), here is using just one of the
meanings of jouissance as a jouissance of the body (Evans, 1998 p10), described by
Lacan as ‘a disturbing dimension in the experience of the body, which renders the
subject unable to experience itself as a self sufficient enjoying entity’ (Lacan, 2018
p217).

However, notice that the concept of jouissance (the word derives from the French for
orgasm) does not have only one meaning and Lacan used it differently and with plural
meanings at different times. Evans (1998) provides a useful account. Jouissance is one of the most important Lacanian concepts (ibid. p2), however, an adequate account is beyond the scope of this thesis. I use the term jouissance in this thesis, in chapter 10 and 11, to describe a kind of ‘erotic joy, experienced at the individual level (as opposed to social or cultural), as necessarily excessive in character’ (ibid. p5). It describes the enjoyment of a libidinally charged or erotic, orgasmic, pleasure, or a state of bliss, that is both pleasurable but at the same time painful, and requires paying ‘the price of suffering’ (ibid. p6), and so goes beyond pleasure. So it has a paradoxical character, as something to be enjoyed ‘without too much anxiety’ as we endure the feeling ‘of being in danger’ (ibid. p5). In other words, jouissance is a kind of excitation that goes beyond pleasure, and even becomes deathly.3

After the mirror stage the individual strives for a full sense of the self, self-awareness by continually seeking cultural, social relations that appear to provide a meaningful, purposive role in life.

These efforts, at least, are sometimes revealed by a person’s apparent assumptions, norms, prejudices and behaviours. And these strivings for identity are most evident in different kinds of communal formations or memberships. For example, from being a member of a gang on a housing estate, to a member of a political party, or of a church, or a gym, or a social class, or an academic/professional body, or a group with a particular identifiable feature (ethnicity, age, gender, sexuality, and so on).

Social norms function as demands on individuals to believe and behave in certain ways. They do this through discourse, signifiers of meaning, not necessarily in words but always through language (signs), and in social contexts. Socially accepted language structures, or symbolic orders, fix particular truths for domains of values for signs or signifiers of meaning.

This theoretical framework provides an explanation for how neoliberal pragmatism (the political-economic philosophy that uses the scientific-political knowledges legitimised by (radical empirical) pragmatism) exercises such power over the human psyche, and why, as a result, the anticipatory care paradox is able to increasingly intensify harm.
There are four main conclusions:

First, human subjectivity is always an alienating identity (‘the finally donned armour’), because the individual has no choice, as a social being, but to try to make sense of her feelings of fragmentation by forming conscious beliefs through meanings created and fixed in discourse structures by symbolic social norms, and their legitimised truths.

Second, Lacan’s discourse structures are based on the way discourse exerts agency through power by creating meanings for language based on legitimising truths, and can be used to analyse and disentangle discourse effects.

Third, the individual, under neoliberal pragmatism, is the necessary labour, raw material and consumer, in a battle, in a war, for possession of her identity. Anticipatory care, and its pastoral power, a) subjugates the individual to her objectivisation as raw material and care-labour, as the screened patient (in advance, ante-); and b) objectivises her in the constitution of her subjectivity as the care-consumer, the treated patient (taken in hand, -capere).

Fourth, this process is anti-democratic and destructive. It serves the demands of neoliberal pragmatism for innovation, in the name of care, whilst, beyond care, it increasingly harms. The individual’s subjectivity: her consciousness, is a) as care-labour, alienated, by agreeing to be diagnosed, from her reality as being harmed; and b) as care-consumer is alienated, by agreeing to be treated, from her reality as being harmed.

NOTES

1 In the Master discourse, for example, the agent, is S1. S1 speaks to issue orders to be obeyed, but the content of these orders is not based on any consistent logic. This is why, the position of truth is represented by S, notation that indicates here chance of circumstance, inconsistency, or inadequacy. For example, a feudal Lord, in the Middle Ages, may have occupied the place of S1 as agent. Such an individual’s authority and power would be based upon, say, historic conquest and title, rather than any knowledge he possesses, and his orders largely determined by his circumstances and position in society.
In the *Hysteric’s discourse*, H, $S$, is in the top left position of agent. As $S$ represents inconsistency or a kind of inadequacy, here $S$, as agent, is an agent of doubt and takes up a questioning attitude towards, say, a social norm, or authority. Such an individual may be represented by a person offered a commodity such as a screening test but is unconvinced that this is a good thing.

In the *Analyst’s discourse*, A, the agent is ‘a’, where ‘a’, in a sense, represents what cannot be completely contained within the logic of the structure. So, this might be the place from which contradictions arising from social norms are expressed. Thus, when speaking as agent and as ‘a’, she may reflect back to an ‘other’ a contradiction in the other’s speech or behaviour. For example, ‘a’ might state to an ‘other’: “You say you didn’t think you needed an operation and yet you agreed to one”.

2 For clarity I have omitted two diagonal arrows here, from Truth to Work and from Product to Agent. These represent resistant discursive powers within the structure. These diagonal arrows would show, for example, how the patient’s dissatisfaction with the test result will lead back to, or exert further force on the agent position to incite the production of more anticipatory care. The double bar at the bottom indicates that the patient, unconscious of her dissatisfaction is also unaware of the nature of the objective knowledge that warrants the programme, its truth: the collateral harms that are de-valued by its subjective basis and neoliberal, exploitative nature.

3 Evans describes the multiple uses of the concept of jouissance used by Lacan over time – and emphasises that ‘the term jouissance does not retain a stable meaning’ (Evans, 1998 p2). In Evan’s account Lacan, over time, comes to uses the term so that that is ‘always marked explicitly by the dimension of sexuality’ (ibid. p4). Initially this is as sexuality with a ‘distinctly biological flavour ... equated with ... orgasm’(ibid. p4), then later as either the ‘paradoxical satisfaction which is found in pursuing an eternally unsatisfied desire’ (ibid. p5), or, alternatively ‘as that which desire aims at’ (ibid. p6). Lacan also relates jouissance to a so-called radical ethical stance, in other words a decision is made not in terms of either a rational (Kantian) imperative on the basis of avoiding personal pain (the pleasure principle) but in terms of the ‘enjoyment’ of jouissance, that ‘implies the acceptance of death’ (ibid. p7) that goes beyond the pleasure principle and ‘makes possible the ethical zone’ (ibid. p8). There is a description of a jouissance of the body, such that after castration ‘has drained jouissance from the body, there is always a certain amount left over’ (Evans, 1998) as a ‘disturbing experience in the dimension of the body’ (Lacan, 2018 p217)

Evans also provides a useful account of jouissance in a cultural context, wherein capitalism has ‘derailed’ the organisation of individual jouissance such that now enjoyment can only be achieved through the enjoyment of the other (Evans, 1998 p20).
Subjectivities of care, a case history of alienating identities

Introduction

The purpose of this chapter is to show: a) how anticipatory care, in general, is part of determined, even coercive, attempts to capture the consciousness, and, therefore, the beliefs, of individuals; and b) how these attempts sometimes fail. This chapter also shows how the formation of subjectivity takes place through institutionalised, or social, control of individual agency and freedom even as, at the same time, it creates an illusory sense of personal agency, and freedom, for the individual.

In this chapter I present a discourse analysis, using Lacan’s structures of discourse, of the effect of the breast cancer screening programme on care-provider subjectivity, and also briefly indicate conflicting care-provider subjectivities in relation to the diagnosis of breast cancer.

I first use Lacan’s university discourse structure (Fig. 7.1), by which screening is imposed on the population, intending to maximise uptake, in the name of saving as many lives from breast cancer as possible. In this structure the agent’s (top left) position is occupied by all-knowing S2, as, the authoritative, and apparently objective, expertise.

I am taking S2 to be represented here by, typically, a body such as the UK Independent Review panel that was commissioned by the government to review breast cancer screening, who, as eminent experts, endorsed the programme and decreed it should continue (Marmot, 2013b).

Second, I use Lacan’s discourse structure of the hysteric (Fig. 7.3), where the position of agent, top left, is occupied by the individual herself, as the doubting distrustful subject, S. This structure illustrates the possibility of a questioning resistance to the imposition of any symbolic law, including that of cancer screening.
The cancer diagnosis as a product in exchange – the coercion to be a care-consumer

A woman, hereafter referred to as MP, was interviewed on a UK current affairs radio programme in 2012 (BBC, 2012b). The interview took place in the context of a recent government sponsored review of the UK breast cancer-screening programme described in chapter 3. The expert ‘independent’ review panel had decided that the programme should continue, but this was a controversial decision because of the scale of overdiagnosis, and so there was media interest in the implications for the public, and especially women who had had different experiences of breast cancer screening. MP was interviewed, she is a woman who had been invited for screening, had been diagnosed with non-invasive cancer and had undergone treatment for this. She was asked by the radio interviewer to describe her experience of going through the screening process. She described her experience of being presented with that diagnosis, as being ‘railroaded’ into surgery.

In the interview, MP says that although she was told by the surgeon she had ‘non-invasive cancer which may never cause you harm’, and although she says she wanted to just ‘wait and see’ she was then told: ‘they couldn’t tell whether I had cancer or not, there may be further cancer undiscovered by the tests’, and surgery was recommended. At that point she says that she felt: ‘under duress … you are under threat of death at this point, in spite of the fact that they’re also telling you it may never progress.’ She says she felt under pressure of time, and to make a quick decision to agree to surgery: ‘it was made clear to me I wasn’t going to get any more of that consultant’s time … it takes a very strong woman at that point not to do anything … I had to make my mind up … I was railroaded’ (BBC, 2012b)

MP, initially, is aware of the possibility of overdiagnosis: ‘what you have is non-invasive cancer which may never harm you’, and refuses the treatment: ‘in that case I’ll wait and see’ (ibid.). However, the harm of overtreatment is made increasingly invisible, devalued, and made meaningless, when the surgeon incites further fear by suggesting there may be as yet undiscovered cancer. And, eventually, MP says she felt railroaded into agreeing to treatment.
In summary then, her experience shows the element of fear that is induced by the diagnosis and the way it is presented to her, and how she felt pressurised to agree to surgery despite the possibility of overdiagnosis. The care-providers appear to be ‘determined’ that she should have surgery and give her little time to make a decision.

I suggest that this second phase of MP’s experience (in which she does comply, albeit with great hesitation) corresponds to the downward arrow from ‘a’ to $ in the university discourse structure in fig. 7.1. This discourse sells the diagnosis, the commodity or product, to the patient in exchange for compliance with treatment. I am suggesting here that the diagnosis, as communicated and as, metaphorically, on sale to the patient, necessarily carries with it the intended treatment that ‘takes in hand’ the anticipated outcome: death from cancer. So, to refuse the recommended treatment is also to refuse the diagnosis ‘as sold’, and its anticipation of death from cancer.

In Lacanese, the clinicians, from the screening clinic to the surgeon, speak from the position of agency of the Other (capital O): the Other is the imagined sovereign authority with the power to justify and impose treatment recommendations. The Other is the imagined, so disembodied, voice that makes the Law (Neill, 2011 pp31-55).

Fig. 7.1 Lacan’s university discourse structure applied to breast cancer screening
I use Lacan’s university structure, Fig. 7.1, to describe aspects of this process.

First, from S2 to ‘a’ in Fig. 7.1, the horizontal arrow represents discourse that recruits the anticipated patient (MP) as care-labour, that is, as the patient who has agreed to be screened.

Then, second, from ‘a’, the downward arrow to $S$, is discourse that ‘sells’ the test result, the diagnosis, to the patient as care-consumer in exchange for accepting treatment.

![Diagram of discourse in the university structure](image)

**Resistance, consciousness and the hysteric discourse**

MP, despite apparently reluctantly agreeing to treatment, also says she vigorously questions, in effect, the legitimised ‘truth’, or Law, that warrants the programme for the expert practitioners. Her consciousness is not completely captured by the programme’s agency, or truth claim.

The role of her subjectivity, as a product, is an interrogative one in a diagonal relation from $S$ to agency, S2, in the university structure, in Fig.7.1.

At the same time, her subjectivity, as agent, in this instance, and in relation to the law of the screening programme, occupies the top left position, as $S$, in the structure of the
hysteric. She speaks to question the statements, S1, of the experts, along the horizontal arrow from S to S1, in Fig. 7.3, to create new knowledge for herself, S2.

Fig. 7.3 MP’s subjectivity illustrated with Lacan’s discourse structure of the hysteric

This structure is what Lacan called the discourse structure of the *hysteric*. As we can see, as used here, *this is not a pejorative term in any sense*. Instead it illustrates the dynamism of subjectivity in flux, reacting to, and being ‘at war’ with, resisting, a demanding symbolic order, or Other, whose desire clashes with the individual’s pre-existing sense of herself.

Parker describes this thus:

‘The hysteric is called into being as a form of subject but refuses to be addressed, to be understood, and this form of subject has been particularly rebellious against its status as a product, as passive object of capitalism functioning as a form of patriarchy. This refusal of recruitment by the ideological apparatus of capitalism marks the hysteric as one who has
nevertheless begun to grasp how, as Lacan puts it, ‘she is a subject not represented for another subject, but for another signifier’ (Lacan, 1977 p198); she is determined by signifying chains that define who she is for others. The hysteric thus shows us something about the nature of ideology, shows how ideology ‘represents the imaginary relationship of individuals to their real existing conditions’ (Parker, 2011b p90).

Here, the term hysteric is not to be confused with any kind of emotional over reaction, an often assumed understanding in common parlance.¹

So, there are three legitimising truths at work here, in three different discourse structures:

First, in the university discourse, the legitimising truth for elite expertise, S2, is S1. This truth is the assertion that ‘early diagnosis by screening saves lives and is a good thing’, and it works to make unconscious the knowledge of collateral harms.

Second, in the master discourse, the legitimising truth for the screener, S1, who telephoned, and entrapped, MP, is $. This truth is the job description she happens to have, which she follows blindly, but it works to make her feel it is her personal role.

Third, in the hysteric discourse, the legitimising truth, for the anticipated patient $, is ‘a’ – doubt. This truth makes it possible for her at least to try to ‘rebelle’ and to ‘refuse recruitment’ by the expert knowledge of S2, but it works to make her unaware that her identity, her social function, always has to be defined or signified socially, or, in other words, ideologically formed in some way.

The screener as care-identifier or diagnostician, entrapment of care-labour, and the master structure of discourse

To remind the reader, I use the term alienation here, to refer, in general, to the process within which an individual is always adrift with, or in flux with, her sense of wholeness, or empirical unity and purpose, and by which some knowledges are made conscious and meaningful, whilst other knowledges are made unconscious and ungraspable as meaning.² This process is the way ideology enables the individual to attempt (but always fail) to attain a sense of self, identity or subjectivity but only

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1. Parker, 2011b p90

2. This process is the way ideology enables the individual to attempt (but always fail) to attain a sense of self, identity or subjectivity but only
through an alienating imaginary relation with her real existing conditions (Althusser, 1984).

Remember that the neoliberal pragmatist justification for the truth claim that screening saves lives and is a good thing, is partly dependent upon securing public acceptability, and this, in turn, partly depends upon the number of lives the programme can be predicted to save. This, again, depends upon the number of anticipated patients that agree to take up screening, and the viability of the programme is partly judged by this screening uptake.

The bureaucrat of the programme is the screener here, employed by the programme to maximise uptake, and to encourage attendance, for example, with follow up phone calls (Bonfill, 2001). Using the terminology of labour power and production, then, her role is to recruit care-labour that embodies, and will submit for mammography the raw material for the programme: the breast tissue.

Her role, I suggest, is consistent with the position of agent, S1, in the top left quadrant of the master structure (see Fig. 7.2). Her truth, bottom left quadrant, is $S$, where $S$, here, signifies the contingent, or chance, nature of this truth which is down to the job she happens to have, and its job description – her orders.

It is as if the consciousness of the screener has already been absolutely captured by the truth, $S_1$, of the programme: that screening is a good thing, so that she felt justified even in ‘hunting’ to maximise uptake (and apparent productivity in terms of ‘lives saved’), and to impose their belief on others, and being silent on harms. It is as if Individuals fetishise even the assumptions, or legitimised truth, of ideology and then may, by apparently just obeying orders, become agents of excessive control.

I suggest that this is consistent with an alienating process: this where the programme tries to take over, albeit temporarily, the individual’s labour power and body. And it does this through the production of her subjectivity in terms of the conscious belief that the programme is a good thing, regardless of known concerns about the programme’s potential harms which are unacknowledged and made, effectively, unconscious.
Care-providers: an example of two contrasting subjectivities

Here, I describe a debate between two cancer specialists that reveals the front lines of the battle between empiricism and pragmatism. I use this debate to demonstrate contrasting care provider subjectivities in terms of perceived and adopted roles for caring and how these are both constructed by and create discourse.

This debate is based on extracts from a radio interview in 2013 with two interviewees, both breast cancer experts from the USA (Esserman, 2013). One interviewee, Laura Esserman is a breast surgeon who has encouraged the re-naming of the most borderline tissues identified by screening in order to remove the fear and urgency induced by the term ‘cancer’ or versions of it (Esserman, 2019). The other interviewee, Larry Norton, is a ‘deputy physician-in-chief for a breast cancer research programme, and Medical Director of a ‘breast centre’, or foundation, who by contrast with Esserman, tends to be enthusiastic and optimistic about the hopes offered by technological advances, and is more concerned about eliminating even the slightest risks that may be caused by any delays in management (Norton, 2019). So, the interview appears to be set up as a debate over the value for changing the names for screen-diagnoses, over the need for urgency of investigation and further treatment, and over the suggestion that cancer should be ‘refined’ and/or ‘re-defined’ (Esserman et al., 2013).

In the debate between Laura and Larry, Laura wants to rename the borderline biopsy results as ‘indolent’ tumours, to limit the speed and extent of intervention where there is a chance of this being a false alarm, that is, there is a higher chance of this being a false positive. Larry resists this change arguing that it runs the risk of leaving tumours that may turn out to be harmful inadequately treated. Laura urges caution, delay and watchful waiting. Larry commends urgent action, just in case, because the consequences of getting it wrong, breast cancer death, he suggests, are too severe.

Here, I consider how the debate itself, that is, its argument in and of itself, already presupposes that anticipatory screening is a good thing. The debate, then, is over the degree of urgency of the need for treatment. It presumes that screening itself has
already taken place and screening itself is not questioned. The debate presupposes that it is at least possible that screening can differentiate between, and specify the point of difference between normal tissue that will not kill no matter how long it is left untreated (benign, non-cancerous) and abnormal tissue that will potentially kill if left untreated for long enough (malignant, cancerous). In this sense the debate fails to consider, or forecloses, the impossibility of identifying a specific point of difference between the normal and the abnormal. This specificity of the mark of disease, it may be argued, is impossible because life itself proceeds through error, that is through processes that are always intrinsically in error, so that there is always a point on the spectrum of physical appearances and even dynamic performance where the future of tissue is unpredictable – the borderline.

As a brief aside, because I will not go into much detail here, this argument has parallels with Derrida’s critique of Foucault’s writing on Descarte’s cogito and madness (Derrida, 1987; Foucault, 1972). Briefly, Foucault, when tracing the history of the moment of exclusion of the ‘mad’ from legal decision making, argued that Descartes was right to argue that thinking is rational even when dreaming because even in a dream the non-mad person knows who and what he or she is, and unlike the mad person may not assume he or she is a jug or a king or somesuch (Foucault, 1972). So Foucault argued that it was right to exclude the ‘mad’ from juridical (legal) decision-making. However, Derrida argued that this is irrational because how can any individual step outside thought and know whether or not he or she is mad. In effect, Derrida argues that the borderline point between madness and non-madness can never be identified. Foucault’s response to Derrida’s criticism led to a significant falling out between the two men, partly because it was, to some extent, a ‘terrible ad hominem’ attack on Derrida’s whole approach, reduced by Foucault to ‘textualisation’ and ‘small time pedagogy’ (Roudinesco, 2005 p92).

Also, briefly, this debate takes place in the context of other debates and explanations for historical developments through what has been called The Enlightenment. There is a good discussion of this in: The subject of psychology by Venn (Henriques, 1984 chapter 3). To simplify, there was a shift from a basis of knowing the truth of the world in religion towards a basis for knowing truth through individualised reason (expressed most clearly by Descartes in particular) and reflection on experience and
appearance. The concept of the individual as the seat of fully self-aware reasoning: ‘the mind guaranteeing its own rationality – even if underwritten by divine creation’ (ibid. p134), also emerges as the object of psychology and the science of the mind, that guarantees ‘the new order of truth’ including ‘mechanical philosophy, protestantism, an increasingly confident merchant capitalism, and the ‘new’ science of Bacon’ (ibid. p138).

Without pursuing the analogy too far, I note that in a similar way, the debate between Laura and Larry is irrational because it fails to note the impossibility of the borderline between normality (non cancer, or non mad) and abnormality (cancer or madness). Both Laura (perhaps an objective social democratic logical empiricist, say) and Larry (perhaps a neoliberal subjective pragmatist in the making) remain within the Cartesian positivist paradigm for what constitutes the allowable object of knowledge – here, tissue abnormality, as something that rationality, and experiment using sense-data observation will be able to specify and identify. In this way the theory of EBM itself insidiously sustains the oppression of neoliberal pragmatism, it forbids the possibility that tissue abnormality, as universally indicative of certain future illness may not be identifiable even by increasingly detailed and particular technologies. This possibility reflects Bachelard’s identification of the contradictory internal dialectic of an inexact science that only ever produces approximate knowledge that is only ever apparently overcome by the certainties of technological pragmatism, but I won’t explore this in more detail here (Bachelard, 2006).

The exclusion of indolence as a signifier for possibly normal tissue is itself only rational in so far as it relies on Descartes’ cogito, that is, on the rationality of a human who may be dreaming, but is still rational enough to know the difference between the rationality of thoughts in dreams and the thoughts of the mad: in dreams I still know what I am, whereas in madness I may be a jug, or a king, and so on. This cogito, for anticipatory diagnostic medicine however, insists on knowing the point of threshold in life, that marks disease, between the normal and the pathological, as if it is knowable and a truth, that is, as ‘real’ cancer.

The irrationality of this claim to ‘full’ knowledge of the mark of disease is reflected in the Receiver Operating Curve (ROC curve, endnotes fig. 4.1, chapter 4). Therefore
we can say that Laura, and the objective logical empiricist social democrats, in their attempt to challenge the positivist cogito, are not recognising their own irrationality. Instead of arguing about attempts to dissolve ambiguity by specifying thresholds they could argue that a form of madness lies with the positivists and their insistence on knowing the unknowable. And, although Derrida may have been right in so far as he suggested human thought cannot be escaped such that we can never be sure of the madness of irrationality, this deconstruction should not be allowed to lead to the arrogance: ‘a certain kind of madness – the intoxication of power’ (Russell, 2004 p737) of the radical empiricists that reject the metaphysical, but instead should be used to recognise that knowledge has limits.

To summarise then, the characterisation of all screen cancer diagnoses as ‘real’ cancer in the context of anticipatory care is possibly disingenuous, and at best anti-democratic. It is the result of the neoliberalisation of anticipatory care using a positivist philosophy. By not seeing the positivists as ‘mad’ in their endeavour, and instead arguing from within their framework for rationality, the social democrats merely provide ‘evidence’ of an apparently democratic debate, thereby supporting and maintaining the neoliberalisation of care. In other words, the Cartesian philosophy that underpins logical empiricism and rationality as a basis for knowing, also stimulates what has been called a mechanical philosophy - a belief that reason and experimental logical empiricism can reveal all the secrets of nature (Henriques, 1984p 135), it contends that the mad (those disbarred from juridical power for reason of unreason) can be distinguished from the non-mad, and that the normal can be distinguished from the abnormal. Pragmatism as we have seen even then manages to remove the requirement for rationality since all that counts is elitist interest in the intended outcome of interest.

The positivism of logical empiricism is irrational if it claims to know the threshold that specifies disease. However, this irrationality is extended by pragmatism that excludes the cogito altogether as a way of thinking about the human condition. For pragmatism (or radical empiricism as described in chapter 2), to remind the reader, only the elite impressions of the observer of the outcome of the inquiry into actions in terms of their intended effects that count as an empirical experience of value and not any reasoning that may lead up to those effects.
Thus, notice that, so far, I have polarised this discussion as one between positivism and social democracy, that is, within the worlds of logical empiricism and social democracy. In other words I have only used the idea of logical empiricism as a basis for a way of knowing that aspires to be able to provide knowledge that is objective and sufficient for socially democratic practice. Now, however, with Larry’s emphasis on the promise of new technology and the advances it will bring, it may be that Larry’s language is more consistent with a neoliberal pragmatism, than logical empiricism, in which case the cogito isn’t just not mad enough, it just isn’t relevant. For neoliberal pragmatism all that matters is elite opinion and impressions of the outcomes of inquiries into the intended effects of actions on specific targeted problems, public opinion, and increasing the economic productivity of both industry and human capital.

To recap, then, the radio interview in 2013 was set up as a discussion, between two breast cancer experts from the USA. They discussed the suggestion that the diagnosis of breast cancer should be ‘refined’ and/or ‘re-defined’ in order to make treatment seem less urgent because some screen cancer diagnoses ‘grow slowly’, and may never cause harm (and represent overdiagnosis) (Esserman, 2013).

For one of the interviewees, Esserman, I suggest that each of the following excerpts of her speech indicates a care-provider subjectivity that resists the neoliberal pragmatic basis for anticipatory care, and, that she attempts to promote a more objectively based social democratic basis for anticipatory care that does value collateral harms.

A word of caution: speech always contains unknown other possible significations, so the following is not meant to imply that this is the correct or full meaning of her, or Larry’s speech. I present a surface reading – of what it appears to say if taken at face value. In chapter 10 I show how this speech can also function as a strategy of capitalist discourse, that uses what appears to be excessive criticism which deflects attention away from the underlying fundamental ideological co-ordinates, or master signifiers. In this case, what is avoided is criticism of the underlying assumption of this practice, namely that, simply put, the assumption that cancer prevention by
offering screening, that diagnoses borderline tissues, to the asymptomatic, *is still a good thing*.

Her speech, at face value then, signifies the care-provider for *inaction*, in other words, signifies that care-providers should not act in haste but rather wait and just observe over time.

‘Just because you have a cancer doesn’t mean that every cancer is a killer cancer …’, ‘we want to use … *tools* … to figure out how to do less safely …’, ‘ … it isn’t necessarily … cancer … we can adjust our threshold for biopsy so we can avoid doing harm …’, ‘try to make sure … our patient community doesn’t panic over every abnormality …’, ‘ … repeat the scan … if it looks stable leave it alone …’, ‘ … there are a lot of things we could let go of that turn out to be nothing … taking a little time is not going to put anyone at risk …’, ‘ … we need to expand our notions of how to get more benefit and less of … the harms …’ (ibid.).

Conversely, for Norton, I suggest these excerpts indicate an adoption of the subjectivity of the neoliberal pragmatist paradigm for anticipatory care.

His speech signifies the care-provider for *action*.

‘… cancer is not just growth … there’s also the possibility to spread to other parts of the body …’, and in relation to a basal cell epithelioma (a slow growing skin ‘cancer’), ‘… if that is left … for too long … it can cause a whole lot of trouble …’, ‘… Laura mentioned … well … only one of such and such percent can be cancer … if you happen to be in that one per cent it’s a big deal not taking care of it …’, ‘ … sometimes screening does pick up bad cancers… not every cancer is slow growing .. particular kinds … even when … small … are very aggressive … so its both ends’, ‘ … indolent might also be a loaded word because we might say somebody’s got indolent cancer and it turns out not to be …’ (ibid.)

Norton also speaks as the signifier of elite expertise that warrants anticipatory care, to promote the normative fantasy, claiming, that there is this:
‘... tremendous explosion of knowledge about biology …’, ‘we really are making strides and it’s a very exciting future’ and ‘communicating the explosive complexity ... how we’re really deciphering it ... what a really exciting time this is ... how it is going to help individuals ... that’s a very important thing to communicate ...’, ‘... if a lay person who is not immersed in this area tries to understand it all, it will be confusing …’ (ibid. my italics)

Norton, as might be expected, emphasises the individual rather than the collective, and expresses a faith in the potential of technology to do good, with no mention of possible harms.

Perversion

This chapter has shown the power of the anticipatory machinery to capture the discursively structured ‘mental state’, or conscious beliefs of subjectivity of both care-labour (the patient) and care-provider (for example, the screening nurse, or diagnostician). This machinery is discourse to which the individual fixes particular meaning, which, in turn, structures her subjectivity. This induces a subjectivity that is subjugated to its objectivisation as servant to this machinery. The subject constituted in this way believes that anticipation is a good thing, and is unconscious of the repressed but known knowledge of its collateral harms to collective wellbeing.

What is repressed here is the truth of neoliberal pragmatism, briefly put: the subjective elite demand for interventions regardless of collateral harms to collective welfare.

The persuasive rhetoric of elite expertise fixes meanings for language in the symbolic line, through master signifiers: language that asserts the democratic nature of anticipation (its claims of transparency about harms, and of ‘fairness’ to patients). And, it does this in a way that upholds its power to authorise anticipation, and to implement what is, in fact, an anti-democratic mode of care. At the same time, the examples show that the process of subjugation by the demand of an imagined big Other can be resisted.

In this chapter I have used Lacan’s theory and discourse structures as analytic tools. I have theorised and analysed language as meaningful, a) in terms of, and because of,
the use to which it is being put: to support an ideology that anticipatory care is a good thing; and b) because of the way it is contextualised when, for example, uttered by expert authority. This uses Lacan’s idea that a signifier signifies a subject for another signifier. In other words language creates beliefs that guide behaviours that in turn go on to create further beliefs. In this way language shapes normative beliefs that guide behaviours.

This chapter also has implications for theories of the meaning of language. I have shown, using Lacan, that the meaning of language lies in its power to capture (and also to resist the capture of) subjectivity ideologically. This is an extension, for example, of both the postivist Carnap’s (1964) idea that language determines the acceptability of scientific theories about concepts, and of both Pêcheux’s (1982) and the so-called ordinary language philosophy in the UK (for example, Austin, 1956) whereby language meaning is about the intended aim of a sentence. This is where Lacan provides additional insight, where although language meaning is essentially always indeterminate, even so, through prevalent symbolic normative structures, (social reality), some meanings are positively signified whilst others are repressed and made unconscious.

For example, statements such as ‘early diagnosis of cancer by screening saves lives and is a good thing’ both, incites insecurity (signifies danger) and, at the same time, offers a source of relief (signifies protection) in a way that provides a means for subjectivity, or identity, in the form of: a) a feeling of completeness of being (what it feels to be ‘what I am’, as an empirical unity); and b) a sense of purpose: a role based on an idea of what is, and feels emotionally to be, (ethically) good and therefore personally desirable.

The discourse structures are useful because they a) indicate the points at which meanings are repressed; and b) identify the point at which the offer of, say, cancer screening, functions as the object ‘a’, cause of desire, that works on (and perhaps disrupts) the recipient’s existing sense of self, and attempts to capture her identity.

However, there are limitations: Lacan’s theory of discourse structures cannot inform us why, in general terms, a particular individual would be more or less likely to be captured by, or even would resist, a particular ideology. This is because the theory has
been developed through and for use in the clinic, whereas I am applying it a social collective level. I have no access to individual histories. At the same time Lacan does not give us a guide whether to resist oppression, but he helps us to see the choices available. Once the choices and consequences are clarified then reason alone identifies that the crucial, ethical, choice to be made is whether to offer anticipatory care at all. One might say: once the offer is made, it can’t be unmade and the opportunity to be free of the oppressive burden of choice/decision and its associated anxieties is lost.

It is widely acknowledged that overdiagnosis is a problem for healthcare, and much research and many conferences and publications address this issue, but it is nearly always addressed from within a logical empiricist and psychologising framework.

Without the (political and) psychoanalytic approach used here a perspective on human decision making would be lost, a perspective that sees decisions as socially determined under normative pressures working through the always incompletely self-aware subject’s desires, real or imagined demands of authority, and the unconscious. This is very important because it refutes the psychologising assumptions behind so-called Shared Decision Making (SDM). SDM is a concept that assumes a wholly self-aware subject, and advocacy for it is used to sanitise (or at least to give the appearance of democracy to) anticipatory care processes.

What I have done here is to identify overdiagnosis, and other harms, as symptoms, caused by anti-democratic neoliberal capitalist pragmatist forces (described in chapter 3) acting on consciousness (see chapter 5). They are symptoms of anticipatory care, suffered by always insecure and never fully self-aware subjects. SDM for anticipatory care can never be democratic. This is a very important conclusion that asks crucial questions of the personal ethics of care providers.

But, also, as well as causing symptomatic harm and an anti-democratic oppressive burden, this chapter raises another possibility: that this mode of care also provokes a perverse tendency of excessive implementation by carers, as if for implementation’s sake. In the language of Norton, there is ‘excitement’ about the ‘explosive complexity’ and increase in knowledge, and emphasis on how incomprehensible this
technology is to the lay person: *as if* only graspable by experts like him (ibid. my italics).

This excitement about technology not only reinforces the authority of elites to decide what is a good thing for the population at large, but also may reveal an excessive excitement in response to the Big Other of capitalism, innovation and fetishised surplus value and so may provoke desire in the individual for the apparent pleasure or enjoyment enjoyed by the Other (Evans, 1998 p20).

Obedience of the subject to the demand to comply may be, in part, due to the fetishisation of anticipatory care technology, as a feature of commodity fetishism. This works partly through the particular emotional effect of *anticipation*, where pleasure with apparently already accomplished effortless gain, or object, is tinged with anxiety that this gain (or object, that I do yet actually have) might be lost, or might not be enough. However, part of this fetishisation may also involve a repression of the knowledge of harms. It is possible, given this apparently effortless gain of surplus life, that the subject may begin to feel increasingly powerful, aggrandised, in her own right, as if the apparent gain is all her own work. Such self-aggrandisement may undermine the authorial power of the Big Other for and over her, destabilising her sense of herself, her identity, and loosening her subjugation to, and castration by, the Big Other of anticipation.

The question may now be asked: is it possible that the individual may become, in a Lacanian sense, *perverse*, that is reject the castration by anticipation of disease prevention by screening, and seek to become her own Master, her own Big Other? This may, for example, manifest in care-providers as hysteric structures of doubt about institutions of authority accompanied by perverse traits such as an excess application of demands on patients to comply, as if for compliance sake. This is discussed in more detail in Chapters 10 and 11. This ‘perversion of care’ may occur when anticipatory interventions are implemented as an impossible to resist response to the drive of surplus jouissance, not in order to anticipate but simply because a) the individual, by reference only to her/himself, feels he or she is or has the power, and right to decide how, to intervene; and b) because stimulated jouissance is excessive erotically charged enjoyment, elation or bliss (Evans, 1998), and so beyond pleasure,
produced here by actions or interventions that involve danger, as if for intervention’s own sake.

NOTES

1 There was a second woman, DD, who was also interviewed on the same BBC radio 4 Today programme, and was also interviewed for The Times, UK, newspaper (BBC, 2012b; Martin, 2012).

Like MP, DD declined the invitation to screening, ignoring a couple of invitations, saying this was due to fear of what they might find, a fear that she might have cancer, and that this might be confirmed. ‘I was a hypochondriac and I was afraid of what they might find — but that worry was worse than actually being told I had cancer’.

The fear of the possibility of, that she might have, cancer appears to be sufficient for her to dismiss the offer and hide the letter.

After her husband found one of the invitations she says he persuaded her to go for screening. She says she felt conflicted:

DD: Missing my screening appointments was down to stupidity, quite frankly. I couldn't feel any lumps, so I ignored it. But at the back of my mind I knew I should have gone to the appointment ... I ignored a couple of the invitations and then my husband David saw one of them and insisted that I went.

However, once screened cancer was diagnosed and she says a mastectomy was recommended, from the radio interview (interviewer):

DD: ....then I went to a surgeon and he and I wanted to have a mastectomy. And they, they, they, they were agreeing that I should have a mastectomy. But I mean, I could not have lived with a breast that I had cancer in.

radio_interviewer:.....right, even though it might have been, it might have spread no further and you might have...your life might not have been at risk.

DD:.....I had the choice. I, I mean. In some ways, I didn't have a choice, because you know, they said I, I did need a mastectomy, but even if they had said, you, you know, you don't need a mastectomy, I would have gone ahead and had a mastectomy, I even would have gone ahead and had a double mastectomy if they would do it, but they said the other one was fine and that's it’

The screen diagnosis of cancer seems to be sufficient to indicate to her that she must have a mastectomy. She is apparently no longer in fear of a possibility of cancer, but is now ‘certain’ she does indeed have cancer.
At this point DD does not appear to be not conscious of, or is repressing, the possibility of overdiagnosis, in the sense that it doesn’t function as something she can grasp as meaningful. It has no value for her. She has, in a sense been captured by the screening programme’s truth in the Lacanian university structure in fig. 7.1. Namely, that ‘early diagnosis prevents breast cancer deaths’ an effective but partial truth which represses the value of harms.

But, she still desires further treatment and removal of the other breast:

DD: ….I even would have gone ahead and had a double mastectomy if they would do it, but they said the other one was fine and that’s it.

This apparent desire for more treatment suggests that as a subject, S, produced by the University Structure, she is barred from complete satisfaction with the treatment offered, she remains fearful and wants more treatment, or what we can call surplus life-security. She is saved, but at the same time, still at risk.

There are two alienating process at work here. First, the ways social norms make conscious the belief that the individual is apparently acting freely, as if it is a natural and just decision, when agreeing to comply with a social norm of some kind, when in fact the norm leaves little choice but to comply. Here, it is the loss of agency that is made unconscious. This is equivalent to the exchange of potential labour power in the employment exchange under capitalism,

And, second, by making it appear that consuming the commodity for sale, or on offer, by that society, is in the individual’s best interests. Here, the potential personal harms of consumption are made unconscious.

This approach is very similar to so-called ordinary language philosophy developed in the 1930s, largely at Oxford University in the UK, and inspired by Wittgenstein, but which I have not explored in detail here (for an example see Austin, 1956).
Introduction

In this chapter the focus shifts from the individual, as care-labourer, care-consumer and care-provider, to the governing institutions that legitimise new forms of anticipatory care.

This chapter uses an economics-focused approach to identify the impact of neoliberal pragmatism on the effectiveness of healthcare services.

This will establish a basis for anticipatory care as a contradiction, because a) the governmental rhetoric promises the democratic delivery of care in the name of the collective good, whilst b) the practice forbids limits to, and so incites, forms of care that are in fact anti-democratic and destructive of the collective good.

To remind the reader: neoliberal pragmatism refers to a basis for evidence-based healthcare practice consistent with: a) a scientific-political philosophy, based on radical empiricism (thought is an empirical experience so that impressions of an effect of an action are a valid basis for judging assertions that the action is a good thing), and pragmatism (where such impressions are a valid basis for guiding social practices as long as they are publicly acceptable); and b) a political-economic philosophy where social order is best maintained by liberal legislation that prioritises the freedom of the individual to act in ways that best serve that individual’s interests regardless of collateral harms to collective welfare.

In this chapter I use a case history: the marketisation and licensing of a molecular genetic signature, called Oncotype-DX. This test is used to stratify patients who have
been treated for early breast cancer according to the risk of suffering a future recurrence. The test result is the risk of recurrence level, which is used to help the patient to decide whether to have additional chemotherapy to reduce the risk of recurrence. This is always a difficult, and potentially costly decision because the chemotherapy itself is both toxic and expensive.

The context and rationale for the development of Oncotype-DX

Oncotype-DX has been developed for use by patients who have been treated for early (small, low grade, well-defined) breast tumours, many of whom have been diagnosed by screening. Once treated, by a combination of lumpectomy/mastectomy and radiotherapy, the risk of recurrence is generally low (1.5-5% over 5yrs, 5-15% over 20 yrs) (Rutgers, 2018), but additional chemotherapy may be offered to reduce that risk.

There is a demographic/pathologic method for estimating a patient’s risk of recurrence that pre-dates Oncotype-DX, and is, in some countries, still widely used. It is accepted that the test’s risk stratification has limited accuracy, and so some ‘low’ risk individuals, who do not have chemotherapy, do develop recurrences that may have been prevented, and conversely, some ‘higher’ risk individuals have chemotherapy, even though their cancer would never have recurred even without it. The test is a form of anticipatory care and it causes overdiagnosis and overtreatment.

There have been pressures to develop a marketable molecular signature to improve upon the accuracy of the demographic/pathologic test, and so to better target chemotherapy so that it causes less unnecessary treatment and overdiagnosis and is more likely to effectively prevent recurrences. Two types of pressure contribute to this:

*Care related* factors. Chemotherapy is toxic and expensive; more accurate risk estimations ‘should’, at least in theory, reduce unnecessary use, saving harm and costs.

*Economic related* factors. The human genome is the object of much research. Expensive training, techniques, and equipment have been developed to identify the genome’s potential for healthcare, and, for example, to develop the complex algorithms that select out population-based combinations of genes, as so-called
signatures, that are predictive of risks of future disease, and against which individual, personal, genotypes can be compared.

The UK government, for example, has encouraged universities to develop business partnerships to encourage innovation, and these have attracted large amounts of investment monies. And, of course, investors invest because they expect a profitable return.

At the same time, the original existing method of estimating risk (a demographic/pathologic test that is based on individual characteristics, such as age, and pathological features of the ‘cancer’ itself) costs nothing, is free, and is freely available to professional carers online. By contrast, the genetic signature costs in the region of 4,000 United States Dollars (USD) per test.

The claim made by its manufacturer for the test’s increased accuracy, that it is more accurate than the older free method, is a contentious one. Some have argued that the evidence that it is more accurate is poor, and that the test ‘only adds cost’ to care (Baum, 2015).

I won’t explore the argument about the test’s validity or relative accuracy here – suffice to say that if it isn’t more accurate then its use and expense will be automatically harming instead of improving care, as well as causing financial toxicity.

I want to explore the implications for health care effectiveness, even on the assumption that it is actually more accurate than the free original test. And, I will focus on healthcare in the UK.

In the UK, most people access care through a health system funded by national taxation, and it is mostly still free at the point of delivery. This UK system has a definite costed ceiling, and this is a budget set by politicians in parliament.

Before a test like Oncotype-DX can be licensed for use by the UK healthcare system an application has to be made to a government appointed institution (NICE, The National Institute for Health and Care Excellence) that commissions cost effectiveness health technology appraisals. This institution then decides if the new technology is advisable and affordable according to a range of criteria.
Before considering Oncotype-DX any further at this stage I will outline the appraisal process and the conditions for, and implications of, licensing a new product.

**The health technology appraisal process in the UK**

To signpost the reader, I will show that: a) the UK institution legitimising innovatory anticipatory care technologies routinely, and intentionally, *breaks through the ceiling* set for the healthcare budget by parliament; b) this causes increasing erosion of the overall effectiveness of the publicly funded service; and c) this is consistent with the reality of a neoliberal pragmatist philosophy for so-called evidence based healthcare.

First, I introduce two key principles: a) opportunity cost and b) the potential for the introduction of new technology to erode overall public healthcare care effectiveness.

**Opportunity costs**

Spending money on a new technology that is being introduced into a budget-limited service *always* incurs what is called an *opportunity cost*. This simply means that what is spent on the new technology is money that has to be taken away from some other existing form of care, so that there is no longer the opportunity to spend the money on that existing care.

However:

> ‘the basis for how local commissioners and providers make their disinvestment decisions is not clear’, and there is no system in place to identify which care should be replaced by the new technology. Although in terms of maximising population health, ‘this displacement should relate to interventions which are the least cost effective’ (Claxton et al., 2015 p7 my italics).

Such a systematic approach is not what happens in practice, which means that when new technology is introduced in one care domain, ceilings for budgets are broken through at local geographical levels, so that, then, care is displaced, and de-funded by local agencies *on an ad hoc, arbitrary basis*. This is borne out by economists, who suggest that: ‘Given the typical pattern of NHS expenditure, the typical bearer of the opportunity cost is, for example, likely to be elderly and in the last year of life’ (Claxton et al., 2015 p7).¹
An important principle here is that if new technology is introduced and paid for out of the limited NHS budget, and if that new care is less cost effective than the care that it would displace, then, necessarily, the overall effectiveness of the service, that is the health gains achievable by the service, must be eroded. This is because, with this scenario, for every pound the service spends on the new care instead of on the care displaced, there must be less health gain.

The threshold(s) for decisions to license new technology

The decisions to license new technologies are, in part, dependent upon the cost effectiveness appraisal commissioned by NICE, as well as on certain so-called equity weights, applied to take account of public opinion and ‘special’ patient groups.

The cost effectiveness appraisal process produces an Incremental Cost Effectiveness Ratio (ICER), a technical term for what is simply the cost of the new service per unit health gained by it (per QALY gained, described below) (McCabe, Claxton, & Culyer, 2008 p740).

The ICER

The ICER is important because it is required to compare the cost effectiveness of two treatments or tests. NICE uses it as the basis for the decision to grant or refuse a licence. It is calculated by comparing the costs and the benefits of two treatments. In some cases if there is no alternative treatment or test, or the alternative is free, then the costs of treatment 2 become irrelevant.

\[
\text{ICER} = \frac{\text{Cost of treatment 1} - \text{Cost of treatment 2}}{\text{Health gain from treatment 1} - \text{Health gain from treatment 2}}
\]

Health economists perform these calculations using data from surveys of patient valuations of different health states. Benefits are measured using something called a QALY (Quality Adjusted Life Year). One QALY is equivalent to one year of life lived in perfect health. A proportion of a QALY for a given health state can be estimated and used as a weighting when comparing interventions. This can be done, for example, using a time trade off method.
For example:

‘Imagine that you are told that you have 10 years left to live. In connection with this you are also told that you can choose to live these 10 years in your current health state or that you can choose to give up some life years to live for a shorter period in full health. Indicate with a cross on the line the number of years in full health that you think is of equal value to 10 years in your current health state.’ If you say 2 years of perfect health is equivalent to the 10 yrs with current health then the status of your current health is 2 out of 10 = 0.2 QALY.’(Burstrom, 2006 p359)

Thresholds for the ICER, as a limit for determining which new technologies should be licensed, can be described in three ways:

First, there is the economist’s central threshold. This is the term used by health economists to describe a cost effectiveness for new technologies that, if licensed, would not reduce the overall effectiveness of the service. In other words it equals the cost effectiveness of services that the new service displaces. Economists have estimated the likely cost effectiveness of services that are actually displaced by the costs of new technologies, in practice, at £13,000 per QALY gained (Claxton et al., 2015).

Second, there is NICE’s threshold-in-practice. This is the cost effectiveness of new technologies that are actually granted licences for use by the UK NHS, and ‘Currently NICE uses a threshold range of £20,000 to £30,000 per quality adjusted life year (QALY) gained’ (McCabe et al., 2008 p743).

Finally, third, I describe the threshold, not as a number, but as a rhetorical-threshold device. I suggest that, by claiming it has a threshold for licensing new technologies, it makes it look as though NICE is protecting the integrity of the service even whilst it intentionally, that is, knowingly, erodes it. The term threshold may be used to refer to NICE’s apparent threshold-in-practice, but it also serves to conceal the ongoing destruction of the service by NICE.

The rhetorical-threshold device could be termed a fact-taboo (a necessary fact but at the same time impossible and so taboo) to link it to the idea of fact-totems, that is,
numbers used by nation states to ‘prove’ how well the state is doing by various measures, of doubtful meaning and validity, but which serve to sustain support for those in political power (De Santos, 2009).²

**The InCEST (Incremental Cost and Effectiveness Sacrifice Threshold) taboo and sovereignty**

In reality the UK government encourages NICE to exceed the central threshold in order to favour innovation (Claxton et al., 2015). After all, there should, ideally, under neoliberal pragmatism, be no threshold for new technology that might prevent it being marketed and used. After all, as I have already noted, innovation is the life-blood of neoliberal pragmatism, that ensures commodity exchange continues, and that warrants actions as a good thing if they work and are publicly acceptable regardless of collateral harms.

In other words, neoliberal pragmatism, in the name of innovation, effectively prohibits (or makes taboo) any limit to the amount of (opportunity) costs, and effectiveness that may be sacrificed.

This is therefore an Incremental Cost and Effectiveness Sacrifice Threshold (InCEST) taboo I have used the term InCEST taboo, because its function is to maintain the sovereign power exercised by NICE, and it draws attention to the way this contemporary prohibition relates this function to the function of the incest taboo described by Lévi-Strauss, that determine kinship structures for what he called primitive cultures. This InCEST taboo performs the same function, and is also the mechanism that sustains sovereign law and power over culture (Lévi-Strauss, 1969).³

For neoliberal pragmatism, NICE acts as a kind of sovereign power, a law maker, which is, paradoxically, made by the Law (appointed by government), so has to, at least, pay lip service to the idea of a central threshold that maintains service integrity, as if it is a necessary fact. It must also make exceptions to the Law (in practice makes such a threshold impossible, thereby eroding the service).⁴ This enables politicians, in effect, to decide what is ‘normal’ and is one of the mechanisms by which power is exerted over a population. The InCEST taboo prevents society from relating to the simple use value of care (its actual effects), and, instead, fetishises the innovative
commodity (and its imagined effects), and undervalues the harms caused when care is eroded.

NICE’s sovereign power and authority is sustained by neoliberal pragmatism’s fantasy that: the basis of anticipatory care, warranted by radical empirical science and pragmatist liberal politics, is a) objective and b) practised for the collective good, that is, is social democratic.

And, for Lévi-Strauss, the incest taboo is a law that prevents individuals relating with their own blood, a self-referentiality which is symbolic of the simple, but meaningless, use value of any given individual asocial life. Effectively forbidding self-referentiality by the incest taboo is a way of insisting that individuals become, and know how to become, social lives with a sense of social meaning. At the same time, the incest taboo provides sovereign power for an imaginary law-maker (such as a deity) thought to be the origin for the symbolic laws (social customs, totems) that give meanings to kinship structures.

So, there is a paradox of sovereignty here: the law of culture makes sovereignty, but sovereignty is also the law that makes culture.

**Innovation**

NICE has expressed the apparent reason for exceeding the central threshold:

‘Unless you believe that drug companies would be prepared to lower their prices in an unprecedented way, reducing the threshold to £13,000 per QALY would mean the NHS closing the door on most new treatments. And drug companies need the discipline of a critical market to make sure that they recognise that price matters … encouraging an innovative UK research base, or perhaps valuing more highly specific treatments that may be the only option for people with certain conditions.’ (Dillon, 2015 p1)

Thus, NICE implies that the NHS must buy in new treatments, as if ‘new’ is always desirable, and explicitly agrees that in doing this it routinely and deliberately exceeds the central threshold, because, NICE claims, the price is market led, as if reducing prices would be somehow unacceptable to industry, and it does this regardless of the collateral harm to and destruction of the health service.
The market has long pleaded its case for necessary profits in order for business to survive, as Marx noted regarding proposals to stop under-18s working at night in the 1850s: ‘What cynical naïveté … “We think that the increase would be more than the trade, with due regard to its being successfully carried out, could fairly bear.” What mealy mouthed phraseology’ (Marx, 1976 chapter 10, section 4, p 177).

So, NICE’s position is one of cynical hypocrisy. It knowingly erodes the effectiveness of the service, despite its claimed social democratic ‘mission’ to maximise health gains for the population. And it demands this same cynicism of the population and care-providers, if it is to retain its authority.

This also sets up the condition of impossibility for the paradox of anticipatory care by exercising sovereign power over the budget set by parliament in ways that are publicly acceptable and that secure the collaboration of professional carers.

This has caused concern within parliament: ‘The affordability of NICE guidance and the threshold it uses to decide whether a treatment is cost effective is of serious concern. The threshold is not based on empirical research and is not directly related to the budget …’ (Claxton et al., 2015 p7) and has raised ethical concerns for health economists: ‘It would seem appropriate, that the value of the threshold gives the NHS and the people it serves confidence that the opportunity cost of the programme is less than the value of the health gain it produces’ (McCabe et al., 2008 p742).

NICE also argues that there is a need to: a) consider so-called ‘equity weights’, where added value is attributed to health gains for certain patient groups (where a treatment ‘may be the only option’) on the basis of ‘public opinion’; and b) to foster ‘innovative’ research and their ‘advances’ that promise ‘cures’ for the future (Dillon, 2015 p1). But, this argument values some lives at the expense of others: ‘If NICE makes a recommendation on equity grounds it must assume that the health gain foregone by those who bear the opportunity cost is valued less than that of those who receive the benefit’ (McCabe et al., 2008 p742). And there has been a call for NICE to consider the victims of the opportunity costs incurred by new technology: ‘Appraisal committees’ judgments on the cost effectiveness of a new technology must include judgements on the implications for healthcare programmes for other patient groups …’ (Culyer et al., 2007 p11 my italics).
**Oncotype-DX**

As a conclusion to the case history: NICE approved the application for Oncotype-DX to be used within the NHS for an ICER of £22,600 per QALY gained, and in 2008 the estimated cost of Oncotype DX is £1,850 (US$3,650) per test (inclusive of transportation to the USA for analysis) (National Institute for Health Research, 2008).

This is an example where the central threshold, estimated to be £13,000 per QALY gained (that would preserve the integrity of the NHS), is exceeded, and where the lives of those that may benefit from the test are being implicitly valued more highly than those who will lose access to care because of the opportunity cost imposed.\(^5\)

In this chapter I have applied a rational-arithmetic (health economic) approach to a case history of an anticipatory diagnostic test. I have shown this case is an example of the escalation of diagnosis in a cascade of care as it is aimed clinically at reducing harm to many patients that *will have already been overdiagnosed* by screening. This case demonstrates that scientific and political regulation of innovative anticipatory care (where such regulation even exists) will authorise the marketisation and public funding when, *even in the regulator’s own terms*, this reduces the overall effectiveness of services. So, using the anthropological analogy of capitalism as a kind of culture, neoliberal capitalism is shown to operate a form of incest taboo that prohibits limits to both cost, and/or effectiveness-reduction, in order to maintain capitalist social relations, innovation and commodity exchange. And, the regulator NICE is shown to exercise the power of a sovereign exceptionalism.

This effective deregulation of healthcare and delimitation of the expansion of anticipatory care is consistent with the general statements made by NICE, which uses rhetoric that is shown to provide meaning, a signification that continued innovation and commodity exchange are desirable and should be demanded by carers and the public so they will continue to be subjects that implement and consume such care. This rhetoric values innovations as beneficial because they are innovations, and at the same time implicitly de-values and represses the meaningfulness of collateral harms to both health and services.
This is a very important finding as it shows that even the expert powers that are meant to be democratically safeguarding healthcare with EBM (such as NICE) are actually (neoliberal pragmatist) instruments of healthcare’s degradation, and are complicit in the sacrifice of the lives of many.

This chapter provides further support for the argument in chapter 2: that expansion of anticipatory care and its harms are driven by the needs of neoliberal capitalism (to ensure ongoing commodity exchange via continuing innovation), that uses the scientific version for knowing truths as that which can be shown to be useful called pragmatism, which in turn creates surplus economic value and flourishes in the health and academic industries because of neoliberal investments.

Healthcare is only one of many axes along which symbolic lines of power operate to construct and fix meanings. For example there are axes of power along feminist, patriarchal, and imperialist lines as well. For example, health care has been shown to be patriarchal (Dusenbery, 2017; Shahvisi, 2018). The individual in society faces a multitude of social, or symbolic, orders – each with its particular kinds of objects of desire, and its own particular focus. And an individual can more or less adopt a particular relation to each symbolic axis that confronts her. However, these axes are not independent of each other, and this mutual dependency is referred to as intersectionality. The symbolic axes are axes of power, along which both oppression and resistance to oppression act. Such axes represent logics of symbolic orders (or perhaps cultural norms/divisions) and may include such things as race, class, nation, gender, age, ability, etc. The concept of intersectionality presents challenges to state enforced population-based healthcare policies.⁶

Nonetheless, the anticipatory care health technology axis, under capitalism, is an important axis. Its object of desire is the body, health and life of individuals, and it is responsible for a great deal of investment in time and money. And, it has a major impact on both practitioner and anticipated-patient beliefs and practices, as well as being a major cause of morbidity and death (Gilbert Welch et al., 2011).

Under neoliberal pragmatism: institutional power and scientific expertise warrant limitless anticipatory technological innovation. This decides the praxis of healthcare, under the name of Evidence Based medicine (EBM). But, it also destroys health and
the capacity of healthcare services to enhance health and relieve present suffering. As I will show in subsequent chapters, neoliberalism’s taboo on limits to innovation unconditionally demands obedience; this: a) destroys the social bond of interpersonal caregiving with love; b) incites perverse ‘enjoyment’ of interventions for their own sake; and c) prohibits the individual’s potential to realise her own health-in-equilibrium.

NOTES

1 For example: other practitioners, downstream as it were, may find their service is repeatedly de-funded, causing longer waiting lists and more untreated suffering, which means they cannot provide the level of care they would like to. For example, today, for child and adolescent mental health services in the UK, children can be on waiting lists for up to three years:

‘YoungMinds FOI (Freedom of Information Enquiry 2015) found that between 2013/14-2014/15 budgets had been cut or frozen in 75% of Mental Health Trusts, 67% of CCGs (Clinical Commissioning Groups), 65% of Local Authorities. This means over 1 in 5 either froze or cut their CAMHS budgets every year since 2010’ (Young Minds, 2016 p7)

2 Such numbers have been described as ‘fact-totems’, “ this new concept sheds light on statistics as multifaceted cultural objects that traditional conceptions of information are ill-equipped to handle”, where the state acts as the “bank of symbolic capital ... shaping the categories that determine the principles of visions and division of the population in a given territory” Fact-Totems are statistical public numbers that have a high media presence and “A fact-totem is a statistic with high media and public visibility that becomes articulated with central identity narratives of a collectivity” (De Santos, 2009 p468).

For example, NICE’s apparent Incremental Cost Effectiveness Threshold for purchase, may be simultaneously denied and yet still operate as a kind of ‘fact’, an apparent ‘threshold-inpractice’, a de-facto threshold that is not a threshold because NICE can, at any time, break it. It functions as a “cultural object and symbol ... with various meaning in diverse contexts ... embedded in semiotic codes and narratives” (ibid. p467).

The QALY categorises ‘ideal types’ of patients as more or less worthy of intervention, authorized by the state and its systems of control, after Bourdieu (1994) : ‘the bank of symbolic capital ... that determine principles of vision and division of the population’.

With the InCEST (incremental Cost and Effectiveness Sacrifice Threshold): there is a politically and scientifically warranted ‘public’ number that appears to regulate expenditure on new technologies for health industry.

The ‘threshold’ functions as a ‘fact-totem’ a semiotic code, or signifier, that makes sense of the narrative of EBM and fosters belief in the objectivity and validity of the knowledge.
Opportunity costs of anticipatory care – chapter 8

produced by science, the ‘identity narrative’ of medical progress being the result of scientific discovery. By contrast its meaning changes, and in another context, the ‘extra-judicial’ realm of expert and public judgement of fairness, in committee rooms, the InCEST becomes a fact-taboo, it must be disavowed as a threshold.

3 I expand here on the analogy with the incest taboo. I draw an analogy here in order to highlight the double standards, or two faces, of NICE, and its role as a politically motivated sovereign supporting neoliberal pragmatism. The analogy also highlights neoliberal pragmatism as a political-scientific culture, that, in effect, demands societal and citizen allegiance that involves the willingness to sacrifice one’s own life for the greater good. I won’t explore this in detail but this idea of sovereign exception in a state of emergency was developed by Carl Schmitt (1985). Schmitt was a well known juridical authority in Germany in the 1930s and 40s, especially interested in the concepts of sovereignty and exceptionalism.

The analogy is based upon the incest taboo as described by Lévi-Strauss (Lévi-Strauss, 1969). The incest taboo, briefly, functions as a cultural law that presupposes a sovereign lawmaker, and that provides individuals with symbolic rules for social relations, rules that enable individuals to form subjectivity and the always insufficient sense of self or identity. Kordela argues that this taboo functions as a taboo on self-referentiality (it forbids the attempt to make sense of the self with reference only to the self) (Kordela, 2013a). And, it does this because the individual cannot ever be fully self-aware, (so self-referentiality is only ever destabilising). Hence, the individual needs to feel there is a sovereign Other that may provide the desired sense of wholeness of being and meaning for life.

The analogy is between the incest taboo and subjectivity that desires surplus in relation to two laws: a), the Law of EBM as objective, as authorised by NICE, based on a belief in limitless surplus life; and b) the Law of neoliberal (capitalist) pragmatism that demands limitless commodity exchange, based on a belief in limitless surplus economic value.

First, NICE warrants, say, cancer screening as a good thing, that is as if for the greater good. As I have shown, this ideology attempts to induce consumption of anticipatory care. And, I suggest, it prohibits a kind of incest, or self-referentiality: it prohibits the acceptance of mortality; as if life only has use-value and is lived in reference to itself. Instead, anticipatory care demands consumption of care to be exchanged as if for surplus life. This creates a belief system that forms subjectivity with reference to the Other: the law of apparently objective EBM science as authorised by NICE.

Second, this chapter shows that the basis for NICE’s Law as described above is a fantasy. NICE, in reality, acts with sovereignty that is able to make an exception to its nominal commitment, as if a regulator of the market, to the effectiveness of healthcare services. This exceptional sovereignty, instead, prohibits the equation of a commodity with only its self-identity as a use-value, in order to ensure the neoliberal capitalism is able to continue extracting surplus economic value via exchange-value. This neoliberal capitalist ideology, via NICE, exercises a taboo that prohibits any limits to be imposed on the markets potential to realise exchange-value in commodities, by prohibiting any limits on the potential sacrifice of expenditure (cost) on, or cost-effectiveness of, new commodities.
Thus here we see neoliberal pragmatism as a cultural system, with its own form of incest taboo, under the sovereignty of NICE, that warrants and demands anticipatory care ‘as a good thing’, and that requires, for example, the acceptance of overdiagnosis, that manifests as the willingness to sacrifice oneself for the greater good.

4 This is the idea of sovereignty, and the state of exception, introduced by Schmitt:

‘the essence of the state’s sovereignty” must be understood “not as the monopoly to coerce or to rule, but as the monopoly to decide” what constitutes the “normal situation”; the “sovereign [. . .] has the monopoly over this last decision’ (Schmitt, 1985 p13).

5 The ‘American Liberalism’ (Foucault, 2004 p217) of the USA, has gone a step further than the UK, and has even forbidden consideration of cost-effectiveness thresholds as aids to judgments on affordability for public healthcare services (Neumann & Weinstein, 2010).

‘The Patient-Centered Outcomes Research Institute . . . shall not develop or employ a dollars per quality adjusted life year (or similar measure that discounts the value of a life because of an individual’s disability) as a threshold to establish what type of health care is cost effective or recommended (The Patient Protection and Affordable Care Act’ (ibid. p1495)

This suggests, not that the most cost effective treatments must be made available to all, but conversely, that there is no level of lack of care that is not possible in the USA, or put differently, there is no limit to the extent care provision can be reduced.

In the USA, compared to the UK, biotechnology, generally, remain significantly less regulated by the state. Many high-tech diagnostic tests in the USA, are defined as Laboratory Developed Tests (LDTs), including Oncotype-DX™, and do not have to go through independent appraisal and validation of clinical benefit. The FDA has concerns that this is leading to excess medical harms, through both overdiagnosis, and under-treatment, and although it is attempting to enforce more rigorous appraisal of test efficacy, it is meeting strong resistance (US Food and Drug Adminstration Agency, 2015).

Note that I am not advocating a fixed budget as a means of controlling expenditure, but I am saying that even by its own terms, the UK government, which does fix a budget, authorises NICE to regulate the market to, ostensibly, (though not in reality) maximise the healthcare effectiveness of the NHS. In reality this budget is commited to new expenditure on services that involve cuts to more cost effective services.

And, note that in the USA, although there is not a fixed public health services budget agreed by central government, even so, as more services are commissioned and as insurance costs rise, there is increasing financial pressure on publicly funded services to authorise insurance cover for less cost effective services, and increasing financial pressure on those increasingly unable to afford self-funded care or insurance. Even as insurance premiums rise this doesn’t necessarily imply that they can be met by either federal budgets or by personal budgets,
suggesting that they may only be met by sacrificing care elsewhere. For example, a recent report has predicted that the Medicare hospital trust fund will run out by 2026, due to both reduced input (deducted from wages, as wages fall) and increased healthcare expenditure. And, this will happen even whilst insurance premiums continue to rise (Medicare Trustees, 2018).

6 Intersectionality

Intersectionality is a controversial theory in which an individual’s sense of the self, or identity, develops from the interaction between multiple axes of power. This has enabled the analysis of oppression along multiple and simultaneous lines such as for example the experience of being a black woman along axes of race, class, and nation, experiencing oppression in terms of status, poverty and power. To note here is that oppression is thought to be ‘interlocking’ and the whole greater than the sum of its parts.

Meanstream healthcare treats its populations, generally, as if their identity exists along single axes of, for example, gender, disease and age, and as universal so that in effect individuals are interchangeable. But, for the lay anticipated patient:

‘Within this paradigm the multiple axes that people identify with in society intersect with various intensities to affect access, presentation to practitioners, treatment choices and treatment … ’ (Davey, 2011 p280)

and with regards to practitioners:

‘... healthcare practitioners are often unmarked and constantly evade problematisation when researching health care (disparities). Practitioners are intentional beings with intersecting identities working in institutions affected by hierarchies of power, gender, sexuality and other social relations and working with hierarchies of illness and disease. The ‘facelessness’ of healthcare providers in both research and practice must be exposed in future in order to ground more complex additions to our knowledge base and transference of knowledge’ (ibid. p280)

‘Proponents of intersectionality ... suggest’ that ‘benefits include being able to incorporate more patient-centred dimensions that foster situationally specific interpretations’ (Burman, 2003 p293)

Thus, the concept of intersectionality introduces another dimension by which power relations for care and individuals can be analysed. Here, in this chapter, I focus on the limits and possibilities for the impact of the particular axis of anticipatory care technologies on the subjectivities of practitioners. It is important to bear in mind that this does not take into account the simultaneous impact of other axes of power acting on any one individual. This means that the analysis here identifies possibilities and consequences for identity formation in relation to anticipatory care practices but it does not claim to be able to know how any individual identity functions overall.
Two impossibilities

Burnout and the depersonalisation of caregiving

Introduction

This chapter describes, first, how the inter-personal caregiving relationship has its own built in impossibility that may induce a transfer of caring allegiance to anticipatory care.

Second, I show how the neoliberal pragmatist basis for anticipatory care depersonalises both the care-provider and care-labourer (patient), and prohibits inter-personal caregiving with love.

Anticipatory care, the caregiving relationship and subjectivity

To remind the reader: anticipatory healthcare predicts (in advance, ante-) what is going to happen, as some future malfunction, in order to prevent (or take in hand, - capere) future suffering. Anticipatory care may take the form of interventions such as: population-based early diagnosis of cancer by screening (breast cancer screening programmes), or the form of innovative diagnostic categories that identify ‘disorders’ requiring treatment (for example, recently decided mental health diagnoses: ‘hoarding disorder’, or ‘intermittent explosive disorder’).

It is important to bear in mind that, in the way I am using this term, it refers to unsolicited ‘care’ applied to non-complaining, asymptomatic individuals, who have, therefore, not presented with any present suffering, or asked, up front as it were, for help.

I have shown that anticipatory forms of healthcare are anti-democratic and destructive of both lives and care provision. But, one of the reasons these harms, and the anticipatory care paradox, persist, is, I suggest, to do with how this mode of care is
adopted, as if part of their sense of themselves, by both care-providers (clinicians) and potential care-labour power (the future patients).

So, in order to critique, and potentially challenge, anticipatory care, I want to be able to identify the ways that both a) anticipatory forms of non-personal care and b) forms of caregiving that are inter-personal affect the subjectivity of potential care-labour (future patients) and care-providers (the clinicians).

And, here, again to remind the reader, I use the Lacanian notion of subjectivity to refer to the constitution of always insufficient identity, self-consciousness, or sense of self. This assumed sense of identity is not the result of any degree of self-determination. It is formed in terms of a) feeling to be apparently whole, autonomous, and free and b) the adoption of a particular, apparently meaningful, role in society.

But, in order to provide a framework for understanding the full potential impact of anticipatory care on subjectivity, it is necessary, in a sense, to go back a step, to the caregiving relationship itself. This is because the caregiving relationship, may, for many, be understood as an inter-personal, one to one relationship. Whereas, conversely, anticipatory care, applied to asymptomatic populations, is, by definition, essentially non-personal.

In simple terms then, there is a potential conflict for care-providers, between their potential role for non-personal anticipatory care and their role for inter-personal modes of caring. To understand the caregiving relation I turn to Freud and Lacan as theoretical resources.

The caregiving relationship and ‘doing the good’

For Freud, caregiving has a sexual ‘fully sensual’ dimension that is usually inhibited: ‘aim inhibited love, expressed in kindness, masks fully sensual love’ (Freud, 2002 p50).

Freud also draws attention to people’s ‘aggressive tendency’, as ‘stubborn characteristics’ that ‘fundamentally contradict the best intentions one can have regarding the desire to help the other’ (ibid. pp68-75). So, the caregiving relationship
is a ‘masked’ loving relationship, but where the sensuality is inhibited, and where intentions to be kind may be opposed by a stubborn aggressiveness.

Lacan describes how ‘wanting good’ for ‘my neighbour’ requires imagination in terms of my own needs, thus, Lacan observes, how in wanting the good for my neighbour, ‘I imagine their difficulties and their suffering in the mirror of my own … what I want is the good of others in the image of my own’ (Lacan, 1973 p187). Hence, inter-personal caring involves a continual attempt by the carer to meet the needs of the other, through her imagination of the needs of the other.

**The Ego-Ideal and the Ideal-Ego**

In simple terms, then, the individual, in general, is always being confronted with possible forms of subjectivity, of ways of making (only ever partial) sense of herself, as an apparent free unity or wholeness of being, and as with a particular meaningful role for her that she has adopted as if her own.

The caregiver is confronted, perhaps during her upbringing and personal life history generally, or, say, during her clinical training, with the implication that she should be ‘doing good’ for the other. This implication may, in part and indirectly, be delivered by the (symbolic) language of the curriculum, the signifier of authority. And, she, as S, will learn to believe that ‘doing good’ will be possible through the skills she is being taught, and, perhaps, through the technology at her disposal. She will learn this, directly, through the voice of her teachers, the voice of the authoritative curriculum.

In response to the implication that she should be doing good for the other, she will feel a deeply disquieting sense of lack due to an evoked sense of her own lack. In order to assuage this lack, she is driven and compelled to make a decision. This is because, as S, a barred subject, she is never fully self-aware, so never feeling completely as a whole being, or fully owning a role or purpose. Therefore, new voices asking new things of her (symbolic demands exercised through the materiality of language/speech that is her truth, and the cause of her subjectivity) can always destabilise her sense of herself, creating anxiety.

Two things may happen simultaneously: a) she may imagine an authority that desires her to be doing good: through the fantasy that her expert knowledge and skills will
give her the power to do this, and b) perceive what is felt as an unconditional demand for her to do good for the other. Although the demand is unconditional it doesn’t mean she has to obey, it is unconditional in the sense that the demand is made regardless of who or what she happens to be as an individual.

If a) and b) happen, then she adopts a relation with the Law of the big Other and is said to have undergone a symbolic *castration*. Also, if a) and b) happen, she can now make some sense of herself, a) feeling as if she is, an *apparently* free unitary individual, which is her *Ego-Ideal* free to be, or to have the power of, A, and b) as her own role which is said to be reflected back to her, as her *Ideal-Ego* from the Other that she imagines.

**Burnout for inter-personal caregivers**

So, then, for this inter-personal caregiver, her *Ideal-Ego* is her idealised image of herself as someone able to do good for the other.

‘However, her *Ideal-Ego* may be contradicted if the other (the cared for), that she tries to care for, does not respond as she expects, to the care she provides. If her ‘imaginary suppositions’ of the needs of the other are wrong, and the other does not respond as expected, this may threaten her belief in her *Ideal-Ego*, which in turn can destabilise her *Ego-Ideal*: her sense of her freedom and self-unity within the Law of the Other.’ (Vanheule, 2002 p267) ²

Vanheule suggests that carer’s burnout may be due to the repetitive conflict between the carer’s idealised image of her role to fulfil the other’s needs, and the other’s rejection of those needs. Vanheule illustrates this with a case study of a professional carer working with people with educational special needs and mental health problems (Vanheule, 2001).

The carer’s *Ideal-Ego* is to provide loving care and to fulfil needs, but the client response is often to reject this care. This rejection is destabilising for the carer’s sense of herself and incites her aggressive impulses. In Freud’s terms her superego reacts because these would lead to an outlet for consummation of her own emotional energy *at the expense of* the other’s energy, that is, by only harming the other. So, she then
expends emotional effort to keep her aggressive impulses at bay because they would contradict her caring Ideal-Ego.

In time, though, through repetition, the emotional energy required drains her and become exhausting. She becomes increasingly depersonalised, that is, unable to have a personal relation with the other, and withdraws from care. Vanheule suggests that this is the mechanism underlying the phenomenon of professional caregiver burnout (ibid.).

**Anticipatory care removes love from care**

Remember that inter-personal caregiving, aiming to do good for the other, through a one to one relationship, is based on an inhibited fully sensual love.

The inter-personal caregiving relationship is impossible because it always relies upon the attempt to know the other through only the *imagined* suppositions based on the carer’s own imagined needs. But, though the relation is impossible, the carer’s sense of her identity is focused on doing good for the particular individual in front of her. And, though imperfect, the inter-personal caregiver may, at least, remain sensitive to the individual and her potential for autonomy, and choices to refuse care.

Briefly, here, I identify two forces at work inhibiting the delivery of inter-personal care, and, thereby, inhibiting the possibility of caring with love.

First, as I have suggested, the emotional energy required to deliver inter-personal care may become exhausting. This may lead to burnout: depersonalisation, depression and, ultimately, a withdrawal from care. So, then, I also suggest, that the non-personal nature of anticipatory forms of care may provide a possible, and even seductive, escape route for the emotionally weary carer.

Second, anticipatory care provides another force making the individual care-provider susceptible to the voice of the Other. This voice of the Other, for anticipatory care, is received as an unconditional demand for the care-provider to make unconditional demands for potential care-labour (future patients) to comply.

For example, as shown in Chapter 7, the care-providers in the breast cancer screening machine railroaded the patient, MP, in the name of a) maximising screening uptake (the screening ‘nurse’) and b) maximising treatment of screen cancer diagnoses (the
surgeon), in ways that obliterated her potential for autonomy in relation to, and freedom to refuse, that care.

The unconditional demand

The key thing to notice here is that the perceived demand of the Other is unconditional. Unconditional, here, means that the demand is literally not conditional on any individual particularity or peculiarity of either, initially the care-provider, and then, of the potential care-labour. Individuality is obliterated: of both the care-provider and of the potential care-labour.

The anticipatory care-provider may still make imaginary suppositions about the needs of the other, but this other is now a non-personal, non-individual and generalised other. This incites a perversion of care that is explored more fully in Chapters 10 and 11. There is an incitement, because of the fetishisation of technology, the assumption of elite power to ‘know’ what is best for the other, to break away even from institutional regulatory control.

And, the imagined needs of the universal other are based upon an elite expert specialist, and neoliberal pragmatist, assumption that the form of care offered is a good thing. This is regardless of the collateral harms such care causes, either a) directly and visibly to individual lives, b) directly but invisibly as through overdiagnosis or c) indirectly through opportunity costs to access to services and access to care for present suffering, as shown in Chapter 8.

The carer imagines the other’s subjectivity (as ideal Ego) to be the same as her own, so that the carer identifies the other’s needs as if they were her own needs.

To summarise: I have identified two sources of conflict for somebody wanting to care with love, that is, to care but not at the expense of the other. The first is the inherent impossibility of ever knowing exactly what the actual needs of the other are, and the second is the way population-based anticipatory care makes the individual needs of the cared for irrelevant in any case, instead imposing universalised forms of care.

I have used Lacan’s theory of subjectivity to provide added insights into the way anticipatory care makes even attempting to provide inter-personal care with love more
difficult because although it is: a) an especially powerful cause of burnout, it is also b) a readily available way of evading the emotional exhaustion caused by burnout.

I summarise this here on the basis of the ideal Ego, where the ideal Ego represents the carer’s felt sense of her role and purpose. The carer, for example, may be confronted with a curriculum, such as I experienced as a GP in training, that expects inter-personal caring in practice. This teaching provokes the student carer to imagine an authoritative Other, a caring-with-love Other for whom caring with love is a good thing, which, then, in effect, demands the student carer takes on the same role: to do the good by caring with love. This constitutes subjectivity as the carer’s ideal Ego, that is a purpose stimulated by objects such as diagnostic tests, to desire and strive to care in this way.

This attempt to care with love leads to the first conflict, because to care like this requires imagining the needs of the other, needs which can never actually be known by the carer. The theory provides the insight that if the carer gets it wrong and tries to provide care that is not needed then it may be rejected, which in turn contradicts the response the carer expects and confronts her with her apparent failure to care. This contradicts her ideal Ego, potentially leading to aggression, exhaustion and burnout.

Then, with population-based anticipatory care, comes the second conflict. This imposes unconditional demands through guidelines that universalises care and do not take into account individual differences. This symbolic demand of the big other of population-based care does not value inter-personal care with love, and so does not value and consequently de-stabilises a subjectivity formed in terms of caring-with-love, and makes it even more likely that the cared for others’ needs will not be met, and care rejected or ignored. This will simultaneously make burnout as a carer with love, more likely, at the same time as it provides an alternative ideology, and alternative ideal Ego, as a kind of nihilistic and amoral public health bureaucrat of care, no longer concerned about care that is at the expense of the other.

Although I have simplified the argument for the sake of illustration, it still shows how population-based anticipatory care prevents caring with love in two ways as: a) it induces burnout because it does not value inter-personal care with love and so provokes and seduces the carer with an enticing alternative non-personal mode of care.
that also, b) offers an alternative that provides relief from the subjective destabilisation and emotional stress of burnout.

The significance of this is to highlight the fact that anticipatory care is not only always at the expense of the other because its tests are never 100% accurate leading to visible felt harms and overdiagnosis, but also because the ideology of anticipatory care is especially powerful at inducing a subjectivity that does not care about these collateral harms, that is, they are no longer valued or meaningful as a guide to practice for the carer.

Thus, caregiving itself faces two impossibilities: a) ‘doing the good’, which always imposes the carer’s perceptions of what is good onto the cared for, when anticipatory care, once offered, is already an imposition of this kind; and b) the unconditional demand of anticipatory care which displaces aim inhibited care with love and means that care can, and must, be provided without being inhibited by the possibility of harm to, or sacrifice of, the other. This leads to the incitement of perverse forms of care, and of increasing harms, as described in the next chapter.

NOTES

1 ‘Lacan illustrates this through the story involving the 4th-century Christian, Saint Martin, who, as an officer in the army, once ripped up his cape to share it with a beggar. Lacan draws attention to the way Saint Martin shared his cape with the ragged beggar by imagining what this distressed other wanted. Lacan stresses how the need that Saint Martin believed himself to be observing is an interpretation that could just as easily be wrong. Consequently, ‘perhaps over and above that need to be clothed, he was begging for something else, namely, that Saint Martin either kill or fuck him’ (Lacan, 1973 p186).

2 Vanheule describes the ‘double effect’ of the ‘installation of an ego ideal’: ‘It determines the way the subject relates to other persons’ (Vanheule, 2001, p267). It is ‘the point in the Other from which the Other sees me, in the form I like to be seen’ (ibid. p267) and:

‘... it is through the ego ideal that the ideal ego can be anticipated ... understood as the succeeded (sic) version of oneself ... the anticipation of it will always cause a jubilant effect’ (Lacan, 1977 p267)
Neoliberal pragmatism and perversion

The capitalist discourse

Introduction

This chapter uses Lacan’s structures of discourse (first described in Chapter 6), as a theoretical resource for identifying what is at stake when a care-provider forms a sense of self, or subjectivity, in relation to anticipatory forms of care.

In other words, for example, for a breast surgeon dealing with the results of cancer screening, I am seeking to identify the influences on, and effects of, how he/she makes sense of him/her self through her idealised image of her self and purpose as a surgeon providing anticipatory care.

I hope to show that anticipatory care, as a commodity under capitalism, coupled with the impossibilities inherent in the inter-personal, and loving, caregiving relationship (described in the last chapter), demands a depersonalisation of the caregiving relation and a perversion of the way the anticipatory care-provider forms a subjectivity: how she or he makes sense of her or himself, and her or his ‘caring’ role.

And, then, I will suggest that this depersonalisation incites a potential perversion of care and subjectivity with another, fifth, structure of discourse, known as the capitalist discourse. This structure is important because it identifies some unexpected conditions of possibility for caregiving, and how caregiving may become unboundaried, and some of the possible mechanisms that shape the formation of subjectivities that sustain, and may even increase, the harms of the anticipatory care paradox.
From the perspective of the care-provider

Lacan described four structures, and the university structure, top right in Fig. 10.1, illustrates discourses forming subjectivity under capitalism. These were described in more detail in Chapters 6 and 7.

![Discourse Diagram](image)

**Fig. 10.1** Lacan’s discourses of the master, hysteric, university and analyst (Lacan, 1978)

I use the university structure (see Fig. 10.2) here on two levels: first where the care-provider is the *product* of the structure as $S$ being put to work by authoritative expertise, and second where the care-provider functions as the *agent* at $S_2$ putting the patient to work. In other words, the care-provider, say, a breast surgeon, can function as both a product and an agent of this structure.

First, then, taking the care-provider’s subjectivity as *the product*, $S$: here, $S_1$, is the ‘truth’ of anticipatory care, such as ‘breast cancer screening is a good thing because it prevents cancer deaths’, and $S_2$ as Agent, speaks this apparent truth, and may be represented by, for example, the expert elite all-knowing panel of the cancer screening review (Marmot, 2012). Their discourse instructs the screening programme to labour or work, $a$, and, it is implied, since it is a good thing, to work to maximise uptake and treatment of cancer detected. The surgeon at $S$, administrates care for $S_2$, and according to this structure works to maximise treatment of cancer diagnoses.
Second, as care-provider of the programme, the surgeon is also agent, at S2, representing clinical expertise; her truth, S1, is the professional guidance he/she is meant to follow; her discourse demands that the potential care-labour power of the patient does work on her own raw material, her body, by undergoing further tests and treatment, to produce at $S$, the compliant patient as care-labour and raw material.

As I described in the previous chapter, in the first scenario S2, as Agent, as expertise that warrants guidelines, makes an unconditional demand on the care-provider to follow guidelines. In the second scenario, S2 as the surgeon, by providing anticipatory care following guidelines that are population-based, makes an unconditional demand on the potential care-labour power to put him/herself to work as a patient.

The first unconditional demand objectivises the care-provider: the surgeon. This is because the demand is not conditional on the individuality of the surgeon as a person.
However, I want to focus on the second unconditional demand, which also has implications for the care-provider’s subjectivity. This second unconditional demand, made by the care-provider, at S2, obliterates the individuality of the patient, at S. This means that the caregiving relation is no longer aimed at doing good for the other, with love, as if the other is an individual person like the surgeon. The other is now an object. And, this suggests that the surgeon’s idealised image of him/herself (her Ego-Ideal) is, according to this structure: a provider of depersonalised care by maximising treatments of cancers with the aim of preventing cancer deaths, regardless of collateral harms. This may be part of the explanation for the patient MP’s experience of feeling ‘railroaded’ in Chapter 7.

**The destabilisation of the care-provider’s subjectivity by anticipatory care**

Remember that the inter-personal caregiving relationship was described in the last chapter, following Freud, as an ‘aim-inhibited’ fully sensual relationship, in which the superego controls any aggressive impulses that may cause harm to the other. However, with the depersonalisation of the other, the patient, and the removal of love from the relationship, there is now no inhibition of any acts that may cause harm to the other.

This lack of inhibition, of acts that can cause harm, removes limits to the range of permissible acts, and, I suggest, may lead to a feeling of increasing power on the part of the surgeon in his or her own right, as him/herself, and a corresponding weakening of the power of the guidelines over him/her, that ordain limits to his or her actions. And, at the same time, this changing power dynamic may destabilise the surgeon’s subjectivity founded in a relation with the imagined Other and the symbolic institutional authorities and their guidelines, and so destabilise her idealised image of him/herself (her Ego Ideal) as a carer doing the good by preventing cancer deaths.
The weakening power of the Name of the Father

This changing power dynamic may weaken the power of the agency, S2, to be the Law. And, any weakening may lead to a failure of the Law as agency to maintain subjectivity, then to a rejection of the Law and symbolic castration and a subsequent loss of a sense of identity for the care-provider.

I have identified four factors that contribute to this weakening of Power of the Agency of the Law, the big Other, or, the symbolic Name of the Father and that may incite a perverse structure for her subjectivity and a perversion of care. Increasing self-referentiality leads to the ‘I’ of the ego assuming certain powers and permissions for itself, thus: ‘I’ no longer have to care about caring at the expense of the others’ needs, ‘I’ know what is good practice without having to rely on other expert authorities, ‘I’ possess the vitalist power to self-actualise surplus life, and ‘I’ am able to implement my own innovations as necessarily a good thing without recourse to other expert opinion.

First, through the depersonalisation of care: this removes limits to the kinds of care that individual care-providers can provide to the asymptomatic, even if they cause harm.

Second, through self-referential knowledge: This is exemplified by radical empiricism (a way-of-knowing or epistemology described in chapter 2), where thought or impressions are valued as ‘true’ empirical experiences in a subjective and self-referential philosophy for knowing what is right or true as a guide to practice. This ‘thought’, as a valid assertion, provides S1 with the effective truth of the university discourse structure (in Fig. 10.2). So there is already a form of self-referentiality at the base of this university structure that empowers individual professionals (where self-referentiality refers to the attempt to make sense of the self with reference to the self alone).

Third, through commodity fetishism: The knowledge of harms is repressed and made unconscious, which enhances commodity fetishism, the apparent power of a commodity of, say, a form of anticipatory care to be able to create surplus value out of itself simply by being a commodity. This already gives forms of care a power over care-providers that may incite increasing use of this mode of care, as if for its own
sake rather because of any use value (prevention of cancer deaths, say) such care may produce.

Fourth, *through the Law*: (as shown in Chapter 8) This is the sovereign Law that decides what is normal in terms of healthcare policy and demands technological innovation. For example, NICE UK, already prohibits any limits on the marketisation and circulation of anticipatory care commodities through the *InCEST taboo* (Incremental Cost and Effectiveness Sacrifice Threshold taboo). So, already operating within the university discourse structure there is a Law of production that prohibits limits to anticipatory care, regardless of collateral harms.

### Perversion

The weakening of the Power of the Agency of the Law (epitomised by, say, NICE UK and its effects on guidelines) to stabilise the identity of the care-provider (the breast surgeon) may lead the surgeon to increasingly turn to himself or herself to make his or her own Law. This leads to a perversion of subjectivity.

By the term perversion here I am referring to the way an individual’s subjectivity may no longer be constituted through the law of an imagined big Other, because of a failure of, or ‘the fact of rejecting, outside all the fields of the symbolic, … castration’ (Lacan, 2017 p90), and the consequent turn to a self-referentiality by which he/she tries to bring into being her own Law and objectivises the other (the care-labour, or patient). This is described in more detail in the next chapter.

‘What differentiates the discourse of capitalism is *Verwerfung*, … rejecting … castration’ (ibid. p90). However, note that Tomšič claims: ‘Capitalism is not perversion, but it *demands* perversion from its subjects. In other words, capitalism demands that the subjects enjoy exploitation and thereby abandon their position as subjects’(Tomšič, 2015 p151 my italics). The subject is no longer just the every-day neurotic of capitalism fetishising commodities but is incited to become a pervert that enjoys being used by commodities.

### Increasing self-referentiality

In other words, because the power of the Law over him/her weakens he/she *may* begin to feel an increasing lack of sufficient sense for her identity by working according to
guidelines, and a lack of sufficient sense for her self accorded by her role, through her Ideal-Ego, as a preventer of cancer deaths.

There is a loss of sense for the self through, and eventually this may lead to a possible renunciation of, the agency of the Other (the elite expertise that guarantees the guidelines as a good thing). Such a loss of sense of self, or identity, may, in turn, lead to increasing uncomfortable, even unbearable, tension within the surgeon, felt as what Lacan described as *jouissance*, or here surplus jouissance (Lacan, 2018 p217). For a fuller account of the complexities and plural meanings of jouissance see chapter 6.

This surplus jouissance provokes further sense of ever more lack or loss (Tomšič, 2015 p67). And, he/she can only ease this sense of lack or loss by attempting to make sense of her self by reference only to her self. In other words, by attempting to make, and be, her own Law, or agency.

Thus, if the subjectivity of the surgeon, or care-provider, is sufficiently destabilised by anticipatory care under capitalism he/she may become increasingly self-referential. This may lead to a radical change in the structure of discourse that governs her subjectivity.

**The capitalist discourse**

The care-provider may adopt a position of agency in a radically different structure of discourse compared to the university structure. This is the capitalist discourse shown in Fig. 10.2. The capitalist discourse has been described in terms of a generalised perversion (Mura, 2015 p163) because the ‘subjective flaw’ – the failure to achieve a sense of the self, is ‘believed to be corrigible’ – because the individual believes he/she alone can make up the sense-deficit: ‘the subject takes care himself to compensate for the flaw of the Other’ (Lacan, 1987 p265)

Within this structure her actions may be driven by an insatiable lack of sense of, and for, her self, creating what Lacan called surplus jouissance (Lacan, 2018 p217). Her actions are driven by a conviction that the next act will be a solution to this intolerable sensation of surplus jouissance due to this ‘subjective flaw’. But, each act only serves to reinforce her lack of sense, producing more discomfort or surplus jouissance, inciting more action.
In the end, the care-provider is increasingly incited to act, or compelled to intervene by providing care, not with the aim of preventing cancer deaths, but in the attempt to deal with this feeling of destitution cause by the destabilisation and loss of sense of self.

The structure of discourse that represents this subjectivity is the capitalist discourse, described by Lacan:

![Lacan's capitalist discourse structure](image)

**Fig. 10.3** Lacan’s capitalist discourse structure (Lacan, 1978)

This can be compared to the university structure in Fig. 10.2. There are five key things to note. The positions of $S$ and $S2$ are swapped over, this indicates that the individual has made herself into her own law, and that he/she now works through her all-knowing knowledge $S2$. There is also a clockwise movement of $S2$ to the position of ‘other’ and of ‘$a$’ to the position of product. The horizontal arrow from $S2$ to $a$ is lost, which indicates that the agent no longer addresses the other as such, through social bonds of care with love (Declercq, 2006). There is now a downward arrow from $S$ to $S1$, the assumption that the next act will be a solution for her discomfort, so that her truth, $S1$, is produced by him/her in the form of her next act. And, finally, the product is now ‘$a$’ which here is the product of surplus jouissance, that is, the discomfort caused by her lack of sense of her self, that provokes increasing sense of lack, and that, by the arrow back to $S$, incites more action.

Pauwels (2019) provides a good example for the need for caution in taking any speech or utterance at face value. He provides an illuminating account of the way the
capitalist discourse may provide a contemporary strategy by which capitalists (and I suggest healthcare practitioners and scientists too) have developed a particular ‘style of mastery’ (ibid. p58) that sustains the harms of capitalism (and, by extension, of anticipatory medicine). Pauwels suggests this ‘style of mastery’ has been developed since the 1960s and 70s when political protests against global capitalism first emerged (exemplified by the student riots in France in May’68). This style of mastery adopts the position of the position of agency in the capitalist discourse and ‘may be characterised as pseudohysterical’ (ibid. p58). This position excessively questions the gaps or contradictions that capitalist practices cause (or, better, that neoliberal pragmatist practices cause, such as overdiagnosis due to screening) but: a) still remains committed to the unacknowledged and unconscious truth of the master signifier S1 (‘prevention’: that prevention of cancer by early diagnosis through screening is a good thing) and b) because of the excessive and restricted focus on the particular issue hides from view the fundamental ‘ideological co-ordinates’ of neoliberal capitalism and pragmatist science themselves, thus protecting these from criticism.

I suggest that even such apparently well-intentioned efforts to reduce the harms of overdiagnosis such as: a) the cancer specialist Laura’s pleas to change the name of borderline cancer lesions in order to reduce the rush to treatment (see chapter 7) (Esserman, 2019); and b) efforts to promote shared decision-making and attention to patient values (Kelly, Heath, Howick, & Greenhalgh, 2015), may be examples of distracting pseudohysterical neoliberal pragmatist mastery working, albeit unintentionally, to sustain the practices of anticipatory medicine.

In this chapter I have used Lacanian theory as a way of explaining how the care-provider, as subject of capitalism, may be incited to perverse forms of care. But, note that whilst capitalism may demand perversion (Tomšič, 2015 p67), this demand may not be obeyed and necessarily actually result in perversion or perverse psychic structures. This may not happen, or not happen often, or happen only partially or fleetingly, because the capitalist discourse structure itself is inherently unstable. However, it is possible that, instead of a persistent perverse capitalist structure, perverse traits may exhibit themselves from time to time, and in the next chapter I use a case history to explain and illustrate how this may happen.
The psychoanalytic theory provides an explanation for why an individual may develop perverse tendencies because of the demands of population-based forms of anticipatory care within a culture dominated by neoliberal capitalist pragmatism. In summary, so far I have identified four factors that may incite increasing self-referentiality and perverse forms of caregiving by de-stabilising subjectivity: these factors are: a) in this chapter, depersonalisation leading to a lack of inhibition of enjoyment at the expense of the other; b) in chapter 2, pragmatism: the valorisation of elite/expert impressions as a source of truth to guide practice; c) in chapter, 5, commodity fetishism; and d) in chapter 2 and 8, neoliberal capitalism which incites, and prohibits any limits to, marketisation of technological innovations.

All of these weaken the power of the paternal metaphor materialised in the institutions that govern the care-provider, and weaken the power of his or her imagination of the Law of the Name of the Father to stabilise her subjectivity and to fix meaning for her in discourse that ‘intends’ to prevent, say, cancer deaths. Intervention may become intervention for its own sake, a perversion of care illustrated with a case history in the next chapter.

NOTES

Vanheule describes the capitalist discourse by comparing it to, and as a ‘mutation’ of, the Master discourse (Vanheule, 2017). And this draws attention to the effect of capitalism on the subjectivity of the Master of the Master discourse structure. I have elected to compare the capitalist discourse to the University discourse because this is the structure that I think is analogous to the structure of capitalism as described by Marx. This is because, here, I am interested in how capitalism ‘demands perversion’ of the subject, and the possible transition from a subject of capitalism, with a psychic University structure, to a capitalist, perverse, discourse structure.
11

The Oedipus complex and care-provision

A case history of perversion

Introduction

In this chapter, I attempt two things:

First, I use Lacan’s ideas about the Oedipus complex and sexuation to describe the formation of an individual’s very first subjectivity as resulting in a particular kind of relationship to symbolic social power.

Second, I use Lacan’s ideas on perversion, as a rejection of castration, to show how this initial subjectivity formation may sometimes be disrupted and lead to the development of a perverse form of subjectivity.

I suggest that a child’s inaugural subjectivity has an influence on how she or he responds to the demands of other kinds of symbolic authority in later life. I describe a case history of an individual care-provider: a breast surgeon who was imprisoned for twenty years in 2017 because of transgressive care practices. This case, and its elaboration using Lacan’s theory of the Oedipus complex, supports my argument that anticipatory care incites perverse tendencies in care-provider subjectivity and perverse care-provision.

Recap

In the last chapter I described the processes by which four factors: depersonalisation, the pragmatist ‘scientific’ basis for deciding what are ‘good’ forms of care, commodity fetishism, and the neoliberal capitalism’s demand to innovate, all contribute to a weakening of the power of the Name (and Law) of the Father to stabilise and sustain subjectivity and so incite a perversion of the caregiving relation, and of subjectivity of the care-provider him/herself.
Here I use the term *perversion* to refer to: the failure of a symbolic ‘authority’ to provide sufficient sense for an individual’s self-consciousness and sense of self, that leads him/her to become her own authority, which destabilises the individual and her capacity to make sense of him/herself. This leads to a subjective flaw or subjective destitution (Žižek, 1989 p105) that he/she is compelled to strive to resolve with a certainty that the next act of ‘care’ will be the solution for her lack; and that leads to a compulsion to be her own Law and to act and care for the sake of the act (of care) only but without love, to act at the expense of the other, by fetishising and objectivising or depersonalising the other.

In effect, capitalism depersonalises, or de-individualises, the care-provider, who in turn is incited to depersonalise, or de-individualise the patient as potential care-labour power.

And, to remind the reader, the mode of *anticipatory healthcare* under neoliberal pragmatism is an especially potent and fetishised commodity because it is a direct promise of surplus life. The anticipatory commodity and the anticipation *affect*, that is, its emotional impact, combine to trigger a particularly powerful incitement of desire for care and to act, upon the subjectivities of both care-providers (professional caregivers) and care-labour (potential patients), regardless of collateral harms.

**The Oedipus complex**

So, to emphasise and clarify: here I am describing a theoretical elaboration of the formation of the subjectivity of a given individual, as opposed to, for example, the way what could be called everyday capitalism tends to capture and subjectivise subjectivities as neurotic, in society in general. The perverse subjectivity I am concerned with in this chapter is incited by capitalism, and is approached here, initially, by considering the very first or inaugural subjectivity that an individual forms during childhood.

To remind the reader once more, the term *subjectivity* is used here to describe the constitution of an individual’s always necessarily insufficient sense of self or identity, without self-determination, through the symbolic by forming the two-fold elements of: a) the Ego-Ideal: as the sense of *apparent* free agency and of apparent wholeness,
(or empirical unity); and b) the Ideal-Ego: the partial sense of meaning and purpose for a role decided according to a particular authority, or big Other.

**Forming a more or less stable subjectivity**

First I will describe what, one might say, is the ‘usual’ situation, where an individual’s subjectivity is formed that has a more or less stable relation with the big Other. In this situation, according to Lacan, the outcome of interest, or what is at stake, is the *kind of relationship* that the individual develops with the authority of her original big Other. And, notice, that it is the kind of relationship developed in this inaugural subjectivity that sets the pattern for her future relationships, later in life, with other symbolic forms of authority and social norms.

The Oedipal process is multilayered and quite complicated, but it has a rationality that I will trace in simple terms. I use the terms mother and father to describe whatever provides the earliest mothering and earliest fathering functions as described below, so the description is, in a sense, a typical idea of how it works, or, is ‘ideal’. To begin with there is the primordial relationship of the child with the mother, which, by definition here, is the relationship within which the child or baby feels to be of-one with the mothering agency, in every way.

In fact, although one could use either male or female pronouns here, I will continue to use the feminine version, even though Fink (2003 p46) has suggested that perversion is probably predominantly a male structure. As part of a process of becoming alienated from her unity with the mother, the child becomes aware that she is in competition with the father figure for the mother’s love, or, in other words, in competition for what can be described as the satisfaction of her needs by the mother.

This alienation creates anxiety and a feeling of being lacking for the child, who cannot now make sense of her self as whole and, at the same time, separate from the mother. This, one could say, is the original moment of the individual’s insufficiency of self-consciousness that characterises human subjectivity.

The alienation from the mother creates in her a lack, a sense of something missing. So, in order to ease her anxiety and lack, she looks at the father by imagining him as if through the eyes of the mother, to discover what it is in the father that the mother
desires, that she, the child, does not have. At this point, then, the child is ‘propelled into the quest for the elusive key to her desire’ (ibid. p52).

The only way the child can alleviate her feeling of something missing in her, and make sense of her self in this situation, because alienation from the mother is inevitable and permanent, is to then imagine that she is the object of the father’s desire. She switches from being conscious of her mother’s desires for the father, to being conscious of herself as being desired by the father.

This is the important moment, described by Parker, where the desire of the father for the child functions as a kind of ‘paternal metaphor’ for the mother’s desire (Parker, 2015a). The knowledge of the mother’s desire for her is repressed. And this is the first repression of known knowledge, that renders such knowledge inoperative within her psyche, that is, makes it meaningless for the child, and that inaugurates her unconscious (Parker, 2015b p79). This is also the moment of symbolic separation.

However, there is another important, and simultaneous, step in this process. Because she perceives the father as desiring her, the father also, simply by having any desire for anything, appears to be lacking and therefore not all-powerful. But in order to satisfy her sense of loss she has a need to feel fully whole, as she felt before being alienated from the mother. And, she can only hope to have her needs met, and achieve her sense of wholeness if she can perceive the father as whole, that is, as all-powerful and not lacking. The only way she can do this is by responding as if she can be or have the father’s power or authority, and responding to the father’s desire for her as if it is a demand for her to be or to have his power.

Finally, then, she desires what she imagines the father should have to make up for his lack, in order to satisfy her own lack, by, in some way, taking the place of the father, or the symbol of authority of the father. She can have a relation with the symbolic authority of the father figure, which is either a) to be that authority that signifies both his desire and lack, or b) to have that authority. This is the moment of symbolic castration (see also chapter 7).

Her fantasy, then, is that she is the object of desire of the father (making unconscious her desire for her mother’s desire). The father is the barred Other, where the bar indicates the lacking father (or the ‘failing paternal imago’). Her fantasy, is her
perception that she is the object of the father’s desire which she perceives as a demand, in order to satisfy her needs, but which fails to satisfy her needs or to quell her anxiety and sense of lack.

This produces her residual desire, which is to be in the place of the father’s symbolic authority. This symbolic castration inaugurates her subjectivity in terms of her relation with the authority of the imagined big Other and by attempting to be or to have that authority.

**Sexuation and a relation to the Phallus**

As a brief aside, because I will not go into more detail here, the father’s authority is symbolised in Lacanian terms as the Phallus. The Phallus symbolises both the father’s desire and lack. The relationship of the individual to this authority, or Phallus, determines what is called the individual’s ‘sexual position’.

For Freud the Phallus refers specifically to the physical penis, albeit with important symbolic impacts on the formation of subjectivity (Laplanche & Pontalis, 1973 p312). For Lacan, the Phallus, as far as it has a role in the castration complex itself, is symbolic of the Law of the Father (Evans, 1996 p142).² The phallus represents both desire and lack.³

Notice that sexuation does not refer to genital or biological sex, or gender. Instead, the sexual position, or sexuation, is a relation with authority or the big Other, or the Phallus. And, the feminine position is to desire to be the Phallus, the authority, whilst the masculine relation is to have the Phallus.

Thus, in other words, after going through the castration complex, one either ends up as the one: a) who wants to have the desire and lack (to have the Phallus), and to be the one who exercises power with desire and lack (the Phallus), and so strives to gain control of power; or b) who wants to be the desire and lack (to be the Phallus) the one who is the means by which power is exercised as desire and lack (the Phallus) and, in a sense, strives to control the means by which power is exercised. These, a) and b) respectively, stereotypically characterise the masculine and feminine forms of subjectivity (Parker, 2015b p78).⁴
This is important because it has been argued that psychic conflict can emerge if an underlying feminine subjectivity finds it is put in a situation where society demands a masculine subjectivity. This may be relevant to the genesis of psychosis where an individual is said to foreclose castration, that is, to have a psychic structure as if symbolic castration is not, and was not ever, even a possibility. This has been suggested as part of the explanation for Freud’s famous case of Schreber and his psychotic illness, as described by Eric Santner (1996).

**Perversion and subjectivity**

This section is about the consequences of an individual’s failure to form a sufficiently stable inaugural subjectivity, or sense of self, through a relation to the father figure. I will describe this in simple terms, but the interested reader will find a useful and fuller account in Fink (2003).

So, simply put then, to begin with: a) the father figure needs to appear to be sufficiently authoritarian, and b) the individual needs to be sufficiently alienated from its empirical (sensed) unity with the mother, in order for the individual to be able to imagine the father figure as capable of satisfying her feeling of alienation, and her accompanying sense of something lost.

In the ‘normal’ situation, simply by being imagined to desire her, the father does appear, to her, to have a lack, but the individual makes up for this by converting the desire for her into a demand to take the father’s place, in a relation that either has his power (the masculine position) or is the means of exercising his power (the feminine position).

However, if the father figure appears too weak, or too insufficiently whole and powerful, then the individual may be unable to imagine the father figure as capable of satisfying her alienation and sense of lack, to the extent that he/she is then unable to re-interpret and transform her imagination of his desire for him/her as a demand to take his place. He/she rejects the process that would provide him/her with a relation to the father figure, that puts him/her in the place he/she imagines he occupies, that is the place of the Other and the Other’s Law, and either to be or to have his power.
In other words, the individual is said to have rejected her symbolic castration. This means that her feelings of alienation, and of her loss of empirical unity, remain unassuaged and persist. She is now forced to turn inwards towards her own individuality and its discomfort, to find another solution. She is forced to make and to be her own authority or Law.

So, in summary then, a perverse structure results from ‘the fact of rejecting, outside all the fields of the symbolic, … castration’ (Lacan, 2017) due to the ‘inadequacy of the paternal function’ (Fink, 2003 p47). The perverse subject refuses to obey the Law of the Father, and instead has to make her own Law come into being.

The only way she can be her own Law is to make a law that defines acts she can perform, which a) take the form of a fetish of some kind, and b) are acts that she is compelled to feel will and must assuage her feeling of alienation. They are acts that are driven by her subjective destitution. But there are two important consequences:

First, the act always fails to resolve her subjective flaw or destitution, and instead, only reinforces and increases her sense of loss, increasing her compulsion to act again.

Second, the act is performed *purely* for its apparent potential to relieve her feeling of destitution, or, in Lacan’s terms, for the sake of her jouissance or libidinally charged bliss or ‘enjoyment’. Therefore, there is nothing inhibiting her from doing this, that is, acting, at the expense of another individual.

In other words, her acts do not include, or make possible, any inter-personal caregiving relation of the kind that I described in Chapter 9. In fact, perversion objectivised the pervert, and prohibits an inter-personal caregiving relation. And the logic of the pervert may become, for a care-provider: to enjoy at the expense of the other, or perhaps better: I must be enjoyed by the consumption of commodities at the expense of the other.

**Capitalism and perversion**

Capitalism, as I described in Chapter 10, weakens the authority or power of the Other of anticipatory care, and at the same time, through neoliberal pragmatism, alienation and commodity fetishism, incites a feeling of self-referential power within an
individual and a fetish for commodities regardless of the collateral harms that may cause.

Therefore, it is possible that individual care-providers, who have failed to establish an inaugural, more or less stable subjectivity, in relation to the Other, during childhood may already have an instability of, or crisis of, subjectivity that has a perverse structure. They may be vulnerable to being incited by neoliberal pragmatism to practice perverse forms of ‘caring’.

I provide a case history here to illustrate what I suggest is a perverse form of caring by an individual.

**A case history**

I should acknowledge at the outset that there is a trap here. There is a danger that I fall into the same trap that anticipatory care falls into, namely to diagnose an asymptomatic individual on the basis of some criteria diagnostic of perversion. In partial mitigation, I suggest that the acts are sufficiently directly harmful to others, and transgressive of his own institutional norms, to be, in themselves, regarded as symptoms, albeit symptoms felt both by him (as surplus jouissance) and by others. And they are symptoms of sufficient gravity to merit an attempt at explanation.

So, I present a possible explanation of this care-provider’s acts in terms of a perverse subjectivity, whilst acknowledging that I cannot have insight into any inaugural subjectivity he may, or may not, have formed in childhood.

I do argue, however, that neoliberal pragmatism may well have a role in inciting, enabling and prolonging such perverse forms of caring, which, at an individual level, represent an extreme possibility for the anticipatory care paradox.

In this case history, the care-provider’s actions appear paradoxical, because he both a) *over*-treats (with biopsies and mastectomies) women whose test results *have not shown* breast cancer, and b) *under*-treats (by using non-approved cleavage sparing surgery) women *who have been* diagnosed with breast cancer.
And, although some of this caring does generate financial gains for him, because it takes place in private practice, the scale of the harm caused suggests that a purely financial motive is insufficient as an explanation.

The care-provider and her actions

Mr Ian Paterson, a breast surgeon, was sentenced in May 2017 to fifteen years in prison for seventeen counts of wounding with intent and three counts of unlawful wounding. And, then, on appeal, in August 2017, his sentence was increased to twenty years.

Those verdicts referred to 10 victims … Two hundred and fifty have been paid compensation, and there may be more than 1,000 in total.

Frances Perks had 27 biopsy cores needlessly taken from her right breast. Carole Johnson had five unnecessary operations to remove lumps … Marian Moran underwent a mastectomy for benign growths … (Topping, 2017)

A detailed report of his activities and the role of the organisations he worked for has been undertaken (Kennedy, 2015). And the current Secretary of State for Health has announced that there will be a further inquiry (BBC, 2017).

Over-treatment

Local GPs had expressed concerns for many years about Mr Paterson’s overdiagnosis and treatment of benign breast lesions. For example, the following extract is taken from a letter, (obtained under the Freedom of Information Act) sent by a GP to a Primary Care Commissioning Group chairman in 2008:

‘I referred a lady to Parkway with some possible thickening in her breast …

The mammogram was reported as normal but the pathologist still felt it prudent to send her to see a breast surgeon … he did a breast biopsy … showing an inadequate sample (that is, no signs of atypia). In his letter to me he (Mr Paterson) said there was atypia and was advising further operation (Heart of England NHS Foundation Trust, 2015 my additions in brackets).

The GP challenged Mr Paterson who said another pathologist had backed up his opinion about atypia, and that there had been a MDT (Multi-Disciplinary Team)
meeting, which had agreed surgery was indicated. In fact, upon further enquiry the GP found that all of the pathologists denied that Mr Paterson had spoken with any of them, and that there never had been an MDT meeting. The GP writes: ‘My patient realises that Mr Paterson has been untruthful and his motive can only have been money …’

In an MDT meeting, in general it is good practice, for example, for cancer diagnoses and treatments to be discussed by both surgeons and pathologists. The GP is clearly concerned that Mr Paterson is quite boldly making up a misleading story about a diagnosis of atypia requiring surgery and consulting with pathologists and the MDT, and seriously lying to and over-treating the patient.

Under-treatment

In addition to overdiagnosis and treatment he continued to perform procedures (so called ‘cleavage sparing surgery for breast cancers’ that were specifically disapproved of by official surgical guidelines, and he continued to do this even after he had been instructed to stop. He continued this prohibited practice for several years before he was finally suspended.

Thus, as early as 2003, Paterson’s colleagues started raising serious concerns that he was not removing enough breast tissue during lumpectomies and mastectomies, increasing the risk of cancer recurring. But it took four investigations, four reports and nine years before Paterson was finally suspended by the General Medical Council in October 2012 (Kennedy, 2015).

‘… on occasions, a variation of a mastectomy was being carried out; what became known later as a “cleavage sparing mastectomy”. This was not a recognised procedure. Women did not consent to it in any properly informed way’ (ibid. p4).

Paterson’s Law

These contradictory acts are not consistent with even neoliberal pragmatism’s Law of Anticipatory Care. The neoliberal pragmatist Law, in relation to breast cancer, is that diagnosis and treatment of breast cancer maximise the intended effect, which is to maximise the number of breast cancer deaths prevented, regardless of collateral harms.
Instead the two kinds of act are not both consistent with preventing cancer deaths, and are only consistent in terms of harming women’s health through breast surgery.

I suggest, then, that anticipatory care incites perverse caring practices. And, here, as an example, Paterson’s acts have taken place in a neoliberal pragmatist milieu for anticipatory care that, in general, values action regardless of harms, elite expert opinion and the fetishisation of innovation.

For Paterson, it appears that the imagined big Other, and the symbolic signifier of the Other, (for example, the UK Royal College of Surgeons), and voice of the Other, (for example, guidelines for surgical practice) were insufficient to stabilise his subjectivity and to guide his practice, and so he had to attempt to bring his own Law into being. Thus:

‘The Crown’s barrister asked if he was ‘familiar’ with the 2005 guidelines of the British Association of Surgical Oncology (BASO). Paterson replied: ‘In broad, yes, we tend to follow them, but they’re not rules or laws, written in stone.’ He told the Crown’s barrister, Julian Christopher QC: ‘You’re looking at guidelines, I’m treating a patient – that’s where we differ.’ He added that the guidelines were ‘entirely appropriate’ for most patients, but were not a perfect fit for every case. Paterson added: ‘We followed BASO guidelines as being the professional body that oversaw the work we did, day in, day out, as strictly as possible, with the caveat that individual patients didn’t necessarily fit into the guidelines.’ (Vernalls, 2017)

One argument might be that here he is being patient-centred and showing attention to patients’ individuality, but I suggest that his apparent wish to excuse making exceptions to guidelines should be seen in the light of his actions to harm patients repeatedly over many years.

I suggest that Paterson is bringing into being a Law: that destroying women’s lives is a good thing. If so, this would involve a complete negation of even the possibility of care for the other with love, the impossibility of the caring social bond and a relation not with a big Other but with his own self, and so would amount to a perversion.
Note that: a) his under-treatment with cleavage sparing surgery may be aimed, on the surface, at preserving beauty; and b) his over treatment with mastectomies etc., for women without cancer, may be aimed, on the surface, at saving life. Paterson may be attempting to constitute his own Ego-Ideal through the imagined gaze of an Other that is the (m)Other, to form a subjectivity as a being that can satisfy (m)Other’s desires. Thus, having rejected castration, he now brings back into operation what had been repressed and unconscious: his desire of his mother’s desire for him. The Law he tries to bring into being is that women are objects that must be ‘enjoyed’, or consumed, by harming them as if for the sake of enjoyment or consumption or destruction alone, not for any subjective harmful impact as felt by the women as such. In practice this involves providing what he thinks women want so that he is able to imagine that, and feels that, they are pleased with him, a feeling that requires repeated confirmation through their praise of him. I suggest he may imagine that the desire of the (m)Other is to have perpetual beauty and life, and he seems to be driven to risk all, even the ‘death’ of his own social life and standing, to satisfy it.5

This destruction of women may also reflect a more widely practised patriarchal bias in healthcare practice in which women are sacrificed by both neglect and over-treatment (Dusenbery, 2017). There is evidence that women have been under-represented in trials of therapies, and as a result, for example, exposed to excessive drug dosages. Thus, a perverse tendency in patriarchal healthcare may ‘enjoy’ intervention (or neglect), that is, over- and under-treat, at the expense of women.

On the basis of this chapter I claim that Mr Paterson’s transgressive practices are consistent with a perverse psychic structure according to Lacanian theory.

His practice is perverse because the only plausible explanation for the fact that he both under- and over-treated his victims is that he no longer desires, and is no longer capable of, caring with love for the other. As described in chapter 10, caring with love, means caring but not at the expense of the other, and is an aim inhibited fully sensual (sexual) relationship. And perversion defined here is a turn to alternatives to the other person, towards fetishised objects, as a response to the surplus jouissance that accompanies his rejection of castration.
As a perverse subjectivity I suggest that his inability to care with love causes him to try to bring his own Law into being, through an object as a substitute for aim-inhibited relations with the other, as a means of trying to resolve his lack and subjective destitution, and of making sense of himself. In his case he appears to fetishise his patients as objects to be harmed for harm enjoyment’s sake. In the process, perhaps, he attempts to constitute his narcissistic Ego-Ideal, through the eyes of his patients, as a power that is able to meet the imagined desire of the (m)Other, by apparently perpetuating beauty and life itself.

A limitation of this chapter is that it is not possible to know or state why he performs these perverse practices. But, I hypothesise that the factors identified, in the last chapter, that weaken the Name of the Father, and lead to a rejection of castration as described in the Oedipal complex, will all be having an effect on Mr Paterson’s subjectivity regardless of his personal history. These were due to factors caused by anticipatory care practised in neoliberal pragmatist economies: the depersonalisation of both care-providers and patients, the power of elitist pragmatist assertions of truth, commodity fetishism, and the incitement to innovate.

And, crucially, I suggest that the significance of this is that these same factors are operating on the subjectivity of all care-providers of population based anticipatory care inciting perverse tendencies in every day practice and life. If so, this will be causing a tendency, at least, from time to time, for care-providers to feel compelled by a loss of subjectivity to harm as a way of being enjoyed by the fetishised and objectivised bodies of patients through perverse practice and the excessive and paradoxical‘enjoyment’ of the risk and harms caused, the erotically charged bliss of enjoyment, of jouissance that requires ‘paying the price of suffering’ (Evans, 1998)⁶. Jouissance as a concept is explored more fully in chapter 6. I suggest this perverse ‘enjoyment’ may manifest itself in more or less extreme ways in the anticipatory mode of care, as, for example, through the apparent over-enthusiastic persuasion of individuals to participate in anticipatory care programmes as experienced by the patient MP, described in chapter 7.

In effect, population-based anticipatory care both prohibits the provision of caregiving with love and, I suggest, incites a tendency to desire to harm.
NOTES

2 Fink argues that ‘the mother–daughter relationship is rarely eroticised to the same degree’ (as the mother–son relationship) (Fink, 2003 p46), ‘... the father often has an easier time separating the daughter from the mother (though he may not feel it as important to do so not feeling that he is in competition with his daughter as he is with his son) ...’ (ibid. p46), nonetheless if the father is not forceful this could lead to traits of perversion (as a rejection of the Law of the father) in the daughter. But, ‘perversion is virtually an exclusively male diagnosis’ (ibid. p46).

2 For Lacan, the Phallus can also be ‘real’ as in the biological organ, and imaginary, which circulates with mother and child in the pre-Oedipal phase, but in this work I am only concerned with its symbolic function (Evans, 1996 p142).

3 In a sense, desire is a residual longing, and lack is the underlying insufficiency of consciousness that comes into effect as soon as the individual receives the demand of the Other, the Law of the Father. The child feels the desire of the Father as a demand for proof of love. But this demand of the Father is in a relation (a dialectic) with the child’s alienation, and the wishes of the child to satisfy its own need for enjoyment (having being forced by the father to give up enjoyment of the mother). Lacan argues that it is the difference between the two: a) the demand of the Other; and b) the wish to satisfy its own needs, that leaves a residual desire.

“... in the primordial relation with the mother’ (Lacan, 2002e p580) apparent unconditional love becomes a demand that commands the child to exclude any other possible source of satisfaction of its needs, it constitutes ‘the power to deprive them (the needs) of what alone can satisfy them (the child)’ (ibid. p580 my additions in brackets). ‘... the very satisfactions demand obtains for needs are debased ... to the point of being no more than the crushing brought on by the demand for love’ (ibid. p580).

4 The sexual non-rapport: this is relevant to the impossible fully ‘aim inhibited’ fully sensual caregiving relationship described in chapter 9. This is also known as the sexual non-rapport.

‘... one can indicate the structures that govern the relations between the sexes by referring simply to the phallus’ function. These relations revolve around a being and a having, which, since they refer to the phallus, have contradictory effects: they give the subject reality in this signifier, but render unreal the relations to be signified on the other.’ (Lacan, 2002e p582)

In other words, in a relation it is impossible for one to have the phallus and the other to be the phallus, hence the non-rapport – this is the contradictory effect. And, the structure constitutes a subjectivity that enables him/her to have an (always insufficient and failing) sense of self in the signifying chain, so makes it real, but actually makes a relation between the sexes as such impossible, or unreal.
This may have some explanation in Freud and Lacan’s concept of the death drive, which is complex and I won’t attempt to go into detail here. Notice, however, that in 1938 Lacan describes the death drive as ‘a desire to return to the pre-oedipal fusion with the mother’s breast, the loss of which is marked on the psyche in the weaning complex’ (Lacan, 1988). Lacan’s ideas change over time, however, and by 1964, Lacan suggests the death drive is an aspect of every drive (Lacan, 1977 p257) leading to its own extinction, repetition, and excess jouissance where ‘enjoyment become suffering’ (Evans, 1996 p33), where the drive is in general, simply put, the kind of force produced by cultural discourse structures, that create jouissance and are ‘enjoyed’ and put to work in subjectivity formation.

‘Enjoyment’ here refers to jouissance, a term used here to describe the paradoxical feeling of bliss, or ecstasy, or elation: excessive erotic joy or pleasure associated with experiencing danger (even of death) and risk, that is beyond pleasure. The demand to enjoy in this way may be induced if he has rejected castration and experienced a kind of subjective destabilisation or destitution. For further discussion of jouissance see chapter 6, and there is a useful account in Evans (1998)

At the same time, note that each time harm is caused this may conflict with his narcissistic Ego-Ideal as someone who is apparently perpetuating beauty and life, a conflict that may create more demand to enjoy, more jouissance. This is why in perversion it is theorised that the transgressive practices will accelerate. In Mr Paterson’s case he showed that he failed to cease his transgressive activities despite repeated warnings consistent with an irrepressible ongoing drive to consume his fetish until his arrest. As Vanheule (2017) suggests:

‘What is produced is surplus-jouissance, which, in the next step, fires the Unbehagen or crisis at the level of the individual. The arrow from a to S in the formula (see Figure 10.2) makes clear that this object a plagues the subject, which again creates the move from S to S1.’ (Vanheule, 2017 p32 my italics)
Conclusion

Contributions to knowledge, and epistemological reflections

This thesis is structured as a series of inquiries into different aspects of a mode of healthcare. It began several years ago as a personal attempt to understand why population-based unsolicited anticipatory diagnostics programmes are so enthusiastically embraced by some clinicians, authoritative medical institutions, political powers, and the media, even whilst this mode of care is being severely criticised, because of the harms it is causing, by authoritative, but often not industry linked, health sciences experts concerned about overdiagnosis.

As a GP for twenty years I had become increasingly perturbed by the increasing numbers of laboratory and imaging investigations being performed, even where the risk of pathology is low, and by the steady increase in the workload of primary care due to population-based screening programmes. This healthcare problematic has become symptomatic in the recent crisis to hit the Cochrane collaboration after it expelled one of the most ardent and respected critics of screening programmes, Peter Goetzsche (Gøtzsche, 2018), promoting a flood of resignations from the board (Inga, 2018).

As introduced in the preface I have used six key ideas as sites for analysis: language, subjectivity, capitalism, science, health and doing the good. The object of the critique is unsolicited or asymptomatic population-based anticipatory healthcare diagnostic practices within neoliberal capitalist economies. The critique challenges, and takes place in the context of, existing dominant, or commonly held standpoints, or normative values on these six ideas. My own standpoints, or normative values, are summarised in the introduction.

I use the first idea, a particular idea of language, to analyse discourse in practice. Language, used here, refers to discursive practices, such as persuasive rhetoric used by experts, which has effects on beliefs and behaviours by producing normative
values for effective truths or knowledge. Angermuller (2018) provides a useful summary and historical survey of this field. Here, the term normative refers to a value, that is felt to be socially approved as moral, that an individual feels she should have and which, she feels, should guide her behaviour. Language is theorised here as constructivist, in the Lacanian sense that it shapes individual subjectivity, for a subject always divided between the conscious and the unconscious, to provide an always necessarily incomplete sense of self and purpose, through such effective ideological truths. Such truths are effective precisely because conflictual knowledge is made unconscious and unacknowledged, and so ungraspable as meaning anything. (for an overview that compares and contrasts Foucauldian and Lacanian concepts of discourse see Hallward, 2011).

I use this concept of language to analyse discourse to identify more or less normative values applied to anticipatory care in practice, and I suggest that language has produced a hierarchy of normative values for the other five ideas: subjectivity, capitalism, science, health, and doing the good.

This idea of language is consistent with both ordinary language philosophy (Austin, 1956), where the meaning of language is thought to reside solely in the effects that it has in social and individual practices, and is also consistent with the idea of language used by Lacan, where language, the symbolic, is the means by which subjectivity is formed, although always incompletely (through castration) and provides both the meaning-making and repression of meaning necessary to sustain subjectivity, that is nonetheless always lacking.

A potential criticism of this use of language that produces effective truths is that it leads to a relativistic view of truth, plural unlimited truths, a view that is permissive so that ‘anything goes’, leading, it is claimed, to oppressive practices that are able to ignore scientific truths (such as, say, empirical evidence for climate change) (Angermuller, 2018 p1). However, although I suggest language is constructivist, that is, is the truth that causes subjectivity, albeit always in flux and insufficient, by shaping beliefs, at the same time I claim, and show in the analysis, that language also sets limits to hierarchies of acceptable truth within the bounds of what are empirical ‘facts’ observed by science.
I will indicate the epistemological boundaries, or opposing standpoints, for hierarchies of values for effective truths. Language produces normative hierarchies through discursive practices within a neoliberal pragmatist social reality based on the five ideas: subjectivity, capitalism, science, health, and doing the good.

**Subjectivity**

The social reality uses language that psychologises a subject valued as if a fully self-aware and fully responsible individual, as if her beliefs are independent of that social reality. This is language, for example, that transforms the signification of overdiagnosis as harm into a fact-number signifying transparency as if this enables the evaluation of pros and cons in a fair, democratic, way.

By contrast, I use Lacanian psychoanalytic theory applied to the case histories, to claim that the individual is never fully self-aware. This means that the offer of anticipatory care: a) exploits desire by provoking anxiety and insecurity which incites a desire for security (see chapter 7); b) depersonalises care-provision which inhibits care with love, and demands care that is universalised and requires necessary sacrifice of the other, that causes burnout for caring with love, as well as providing a way to escape burnout through an alternative mode of care, without love, (chapter 10); and c) may contribute to the destabilisation of subjectivity that may lead to perverse tendencies to harm for harm’s sake (chapter 11).

These effects on subjectivity are due to discursive forces and practice. Although in chapter 7 the case illustrated a personal hysteric resistance it should be noted that I haven’t attempted to explain why some individuals may resist or not. Note also, that the asymptomatic public often does not comply with anticipatory care programmes, either screening invitations or risk stratifications. For example, in the UK breast cancer screening uptake is under 70%, and uptake for cervical cancer screening in the UK has decreased to a 21 year low (Matthews-King, 2018). The reasons for such non-compliance are no doubt multi-factorial but it may, at least, suggest that individual subjectivities are not always successively captured by the ideology of anticipatory care.
Conclusion

The political economy

The prevalent social reality today is neoliberal capitalism. In terms of the normative, or effective truth, of anticipatory care diagnostic technologies as commodities, the hierarchy is constituted in terms of the tests being valued for either, a) their use value: the prolongation of life; or b) their apparent power to create more life for more life’s sake, surplus life, more for more’s sake. Neoliberal capitalist discourse suggests the tests are a good thing because of their use-value, for example, they may prevent cancer deaths.

By contrast Marx’s analysis of capitalism suggests tests are desired because they are fetishised. For example, the patient in chapter 7 says she would have been happy to have both breasts removed, the screening nurse seems to pursue a greater uptake of screening by applying pressure on the patient to comply, and NICE UK has a policy that promotes innovation, more advanced technologies, even where this will degrade care service effectiveness, in its own terms, of costs per QALY.

In terms of innovation, it should be noted that sometimes NICE UK, for example, does refuse funding for technologies on grounds of cost effectiveness, so the claims by NICE that it regulates expenditure are not without some grounds. Nonetheless the normative value of innovative technology as an effective truth to guide practice does seem to be greater than the normative values of some existing care services in the social reality of neoliberal capitalism.

Science

The scientific and social reality here is mixed: for social reality in neoliberal economies, language constitutes a hierarchy of normative values based on the truth of the findings of empirical scientific inquiry. On the one hand, for logical empiricism, a scientific truth is based on the effects of an intervention regardless of the intended effects; on the other hand, for pragmatism, the scientific truth is based more upon the intended effects of an intervention and decreases the normative values, say, of collateral harms such as overdiagnosis. I have suggested that pragmatist truths dominate, and have greater normative value, because intended effects appear to be used to warrant assertions that anticipatory care is a good thing (see chapter 3), whilst harms such as overdiagnoses are de-valued as harms.
However, the social reality is mixed because there is significant professional resistance through which attempts are being made to counter pragmatist truths by logical empiricists. These include recent criticism of the Cochrane collaboration for its links with industry (Newman, 2019), and inability to tolerate critique from its own members, and, for example, calls from the screening experts in Switzerland to stop its breast cancer screening programme (Biller-Andorno, 2014).

In addition, the incitements to increase anticipatory care that I describe are resisted by those professionals that do recognise and value overdiagnosis as a major problem, as a harm, and try to mitigate this harm by emphasising the scale of harms, the need for better information for patients, and the need for better shared decision-making techniques.

However, I suggest that, as with the discussion between the cancer specialists (chapter 7), that this apparent resistance to harms of overdiagnosis, albeit well intentioned, not only psychologises individuals, but also keeps the limits of truth and debate within the empirical framework, and so sustains the value of the continued search for more advanced technologies of early diagnosis as a good thing, as a normative effective truth, and so actually contributes to continuing increases in harm from overdiagnosis. This has been described as a ‘pseudohysterical’ discourse of excessive complaint that in effect prohibits any challenge to the core ideological co-ordinates (see chapter 10).

Rhetorical devices are used which promote anticipatory medicine as a good thing and repress the valuation of collateral harms as harm. For example, the prevalent bias in health or life sciences uses the language of the gold standard of anticipatory diagnostic tests, justifying this on the grounds that this ‘gold’ means it is the best available, which is disingenuous when ordinary interpretation is, I suggest, that ‘gold’ signifies accuracy. In addition overdiagnosis is described as an unavoidable mal-detection, rather than a mis- (or even dys-) diagnosis or false positive, as if a chance accident rather than a culpable mistake (see chapter 4). This constitutes a hierarchy based on the idea of whether an accurate diagnosis of disease should imply that the disease would cause harm if not treated or whether the diagnosis is still valid and accurate, but only an unavoidable mal-detection, if the disease would not turn out to be harmful. However, again, there is a discursive battle over the meaning of the term disease, (see chapter 4), such that some would use disease only for diagnoses that
would be harmful but this is still framed within limits that insist that health is defined as the absence of disease.

**Health**

Under the social reality of neoliberal pragmatism health is the absence of disease, which makes it into an impossible and aspirational normative value that stimulates innovation and consumption of health technologies. However, there is another concept of health, which is separate to the concept of health of empirical science, and which does not count as having any normative value at all by science. This is Canguilhem’s concept of health as a margin of tolerance for life’s and the environment’s inconstancies (see chapter 1). Canguilhem’s concept of health values as beneficial the eco-biological autonomy of the individual to reset his or her own physiological norms. This makes it possible to value non-intervention, to refuse the aspirational and impossible goal of total freedom from illness, and to, potentially, avoid anxieties induced by anticipatory care.

**Doing the good**

This idea has been approached theoretically using psychoanalytic theory of the sexual relation, burnout and perversion in chapters 10 and 11. However, as a population-based practice, anticipatory care in the social reality is de-personalising of both care providers and patients (or care-labour). And the language of anticipatory care constitutes a hierarchy, or competition, between the normative value of care that is, or is not, at the expense of the other. This, again, is a mixed discursive practice, where language is used *as if* to minimise harm to the other, by apparently allowing the other a free choice based on knowledge of the pros and cons, through, for example, shared decision making techniques that psychologise individuals, even *whilst* what is being offered is population-based and will cause inevitable overdiagnosis for some.

In addition, in chapter 11, I hypothesise that the perverse behaviour of the surgeon Mr Paterson is an extreme example of perverse traits stimulated by the mode of anticipatory care in neoliberal pragmatist social reality as practised in everyday life by many. This is a speculative chapter using psychoanalytic theory in part to provide an intellectually plausible explanation for Mr Paterson’s behaviour but also to suggest a danger posed by anticipatory care that has not so far been recognised. I suggest that there are several factors that incite perversion, as described in chapter 10: the
assumption of power by elite expertise to decide what is good practice, the
fetishisation of the mechanisms of care for their own sake, the institutional
fetishisation of innovation, and the depersonalisation of care that removes love and
warrants harm.

**Epistemological reflections**

My contribution to knowledge here has: a) a relation to *existing* knowledge produced
by today’s normative scientific traditions (logical empiricism and pragmatism); *but* b)
proceeds through the identification of a hole in knowledge leading to a ‘fall in
knowledge’; and c) identifies unacknowledged *repressed* existing knowledge so that
the potentially emancipatory meanings of such knowledge may be revived and
become effective. (Here ‘meaning’ refers to the signification of effective truths in
terms of the way it constructs beliefs that decide what can be regarded as good
purpose, or intent, and practice.)

I have argued that the continued expansion of population-based diagnostic
anticipatory care technologies and programmes is due to the control of effective truths
by neoliberal (capitalist) pragmatism. I have demonstrated that this expansion is an
obstacle to good health for individuals and to effective healthcare services. And, I
have noted that this expansion is meeting both passive resistance by non-compliant
lay citizens, and active resistance by those known as screening sceptics from within
the EBM medical community. But, I have argued that such active resistance based on
the philosophy of EBM, albeit well intentioned, and with some emancipatory
potential, nonetheless ends up: a) psychologising individuals; and b) providing the
empirical results ensuring continuing innovation and exchange for the healthcare
market. EBM, therefore, functions as the epistemological foundation for *continuing*
domination of normative truths by neoliberal (capitalist) pragmatism for healthcare
policy regarding population-based diagnostic anticipatory care programmes.

The findings in this research can be framed, therefore, in terms of surprising
contradictions that reveal unconscious meanings for existing knowledge. For
example:

1. The effective truth that cancer screening is a good thing, even when it causes a
   large amount of harm, and even when patients over value its benefit.
2. The public disagreements between individual experts and the persuasive rhetoric used to promote normative truths.

3. The stark contrast between patients in their trust in anticipatory screen diagnoses.

4. The normative/effective truths warranted by regulators of healthcare innovations on the basis that innovation is a good thing even when it causes harm to overall service effectiveness.

5. The excessive degree to which persuasive rhetoric is used to promote normative and anti-democratic effective truths.

6. The apparently inexplicably perverse transgressive behaviour that appears to practise care that harms as if for harm’s sake

In each case, I have shown how language is used (in discursive practices) to suppress some meanings, and to make them effectively unconscious, so that the normative effective truths and their meanings are conscious knowledge that then maintain their social place as knowledge.

The explanatory hypothesis that I describe is, I suggest, the simplest theory, (and the only alternative that I can identify), for explaining the surprises and contradictions above, and is therefore a serious contender for explanation.

This is, first, Lacan’s psychoanalytic theory, or hypothesis, that subjectivity is structured and constituted by and through social, normative ideologies, and their effective truths, through language, the symbolic, that makes some knowledge and its meanings unconscious (such as unintended collateral harms), and makes other knowledge with alternative and opposing meanings (such as limited and intended benefits) conscious.

And, second, this theory explains the power of the contemporary social reality, the political-scientific ideology and social structure of neoliberal pragmatism, to capture subjectivity. This political-scientific social structure and epistemological basis warrants as truth practices because they ‘work’ on limited intended targets or problems, insists on innovation, and cause commodities to be fetishised because they
appear to promise surplus (profit, meaning and life) out of thin air. This, then, means that individuals have beliefs in, and will exercise excessively, practices that are social policy on the basis that they may achieve a stated intentional good, but are at the same time able to not believe, as harmful, the evident individual and population-based harms such policies cause.

Some of the suppressed knowledges that I have revealed are, for example:

1. That population-based anticipatory diagnoses, such as real ‘cancer’, are often not ‘real’ in the sense that they are not always harmful disease

2. That the pursuit of disease prevention through innovative diagnostic technological advances applied to asymptomatic population-based programmes in industrial western societies is highly likely to be causing more harm to well-being, and health services, than good.

3. The offer of this mode of care is anti-democratic because the perceived value of these technologies is always inflated because of commodity fetishism, and because of the fear and desire induced by persuasive normative rhetoric used by elite interests.

The progressive invasion of practice by this mode of care is driving out the capacity to care with inter-personal love, reduces capacity to care for suffering, and incites excessive coercive implementation, and possibly even occasionally incites perverse care that harms for harm’s sake.

I do not think it is reasonable to claim that anticipatory care should not be offered because of the effects of fetishisation of care, overdiagnosis, and opportunity costs, which isn’t to say I claim it should necessarily be offered either.

However, there is another consequence and epistemological basis for the anticipatory diagnostic mode of healthcare, which identifies a) the depersonalisation of care as well as b) the scientific supposition of a full state of knowledge for human life in terms of the empirically (or statistically), demonstrable specificity of ‘the mark of disease’: the moment of genesis of pathology (or disease). The depersonalisation removes love from care, and the supposition of a full state of knowledge leads to
elite/expert-led unfounded belief in, and desire for, expanding forms of this mode of care. This removes effective regulatory limits to care even though it is at the expense of the other, and incites narcissistic delusions by and of expert power. This is why I argue this mode of care is: provoking an increasing crisis for health and healthcare in terms of increasing collateral harms, removing love from care, inciting perversion, and opening the way for limitless extensions of this mode of care and sacrifice of the unwitting overdiagnosed.

I describe the five main consequences that aggravate harms here:

a) *Fetishism*: scientific ‘truths’ are always transmitted through the social reality mediated by political power, social language and social acceptability, and therefore are always biased towards a particular action. Indeed this is true of all commodities. This is the social reality today, and especially so under capitalism and commodity fetishism. To deprive people of access to technology on grounds that it is fetishised, might be arguable ethically, but is not, perhaps an action that would win a public debate, and is an argument that could be applied to all commodities to a greater or lesser extent. I don’t know whether the offer of anticipatory care should or could be withheld on the ground that it is fetishised.

b) *Overdiagnosis*: is a harm that is not imaginable at a personally relevant level because it never has been personally experienced as such, and could not be by anyone, but overdiagnosis is always inevitable for any anticipatory care, so, at what point does the harm of overdiagnosis, undervalued as a harm as I think it must be, become a reason not to offer a form of care? I don’t know the answer to that for every form of anticipatory care. I might have a judgment to make, or might be prepared to offer information/support to others, but, I would not feel, for example, qualified as a male to comment on screening programmes aimed at women, on this basis.

c) *Opportunity costs 1*: for access to care for present day suffering, here ethical dilemmas arise: for example, future suffering of those whose lives could be saved by, say, cancer screening, could be valued on the same basis, in theory, as suffering occurring today; on the one hand, if care is taken away from some to provide care for others, this seems unfair; but at the same time, if the care being provided already was
provided without taking into account the views of those whose lives, and future suffering, might be saved with new technology, that also seems unfair. With limited resources distribution of care will always leave some better off than others. So, I don’t know if anticipatory care should not be offered on the argument that it reduces capacity to care for present day suffering.

d) **Opportunity cost 2**: if care is commissioned that is going to be less cost effective, so that it is likely, by default, to replace care that is more cost effective, leading to a slow, perhaps almost imperceptible, or easy to disguise, decline in overall healthcare effectiveness, then my view is that fetishising innovation is not a good enough reason to justify this, and that *new forms* of anticipatory care should not be commissioned that are less cost effective than the central threshold (described in chapter 8) despite the pitfalls in the QALY. However, this is not a ground for saying, in general, that anticipatory diagnostic care should not be offered.

e) **Depersonalisation**: of carers and the cared-for by population-based anticipatory care leads to a care without inter-personal love that permits care that is *at the expense of the other* (and is not just care that carries a risk of harm and benefit at an individual level, as for example giving an antibiotic for an infection that might be viral).

Diagnostic anticipatory care *depersonalises* and creates biologically based social division that *permits sacrifices* of others at a population level. It is a mode of care that discursively constructs diagnostic knowledge as if it is a *full state of knowledge* of the human life (as in the ‘gold standard’ rhetoric for screen cancer diagnoses). It *lures carers away* from the already emotionally difficult interpersonal care that population-based diagnostic anticipatory care makes even harder. Alongside other factors I suggest that this depersonalisation *may incite perverse traits*, to harm for harm’s sake. *It is for these particular over-riding reasons that my view is that unsolicited or asymptomatic population-based diagnostic anticipatory care should not be offered.*

Two of the problematics that emerge, then, include: a) truth and science, and how, for Science, ‘unconscious subjective forces … permeate the implementation of its principles’ (Nobus & Quinn, 2005 p19); and b) the insufficient consciousness of subjectivity, as constructed by the social reality of a ‘curious copulation’ between neoliberal capitalism and pragmatist scientism (Lacan, 1991 p103).
Pragmatism, briefly, is an elitist subjective way of knowing ‘truths’ to guide practice, that are asserted on the basis of the desired intended effects of interventions under inquiry, whilst discounting unintended, but inevitable, collateral harms such as overdiagnosis, which are, discursively, made ungraspable as meaning harm.

The thesis has shown how observable, quantifiable, harms and benefits are transformed by language, and put into effect discursively as forces that both promote and critique anticipatory care and its scientific truths. This battle is fought within the bounds of scientific empiricism, and Marx and Lacan are used to show how the ‘truths’ produced by science in this debate are a misrecognition.

**What are the alternatives?**

If I am claiming that population-based anticipatory care is necessarily oppressive and antidemocratic, over valued by care providers and patients alike, causing an invisible epidemic of overdiagnosis, bankrupting services for those suffering illness, causing financial toxicity for individuals, and inciting perversion, then, *What can be done?*

First, I suggest that current attempts to regulate the flow of new technology appear doomed because neoliberal pragmatism has such a firm grip on social reality, but significantly, secondly, these apparent attempts at regulation remain within a neoliberal capitalist and pragmatist scientific framework (see chapter 10), for discussion of how the capitalist discourse sustains neoliberal pragmatist practices). This is important, and although I don’t doubt the truth of empirically verifiable facts, at the same time such science fails to accredit any value to the role of fear, belief, and desire in forming a subjectivity that is never fully self-aware. To do so would require a valuation applied to commodity fetishism itself, something effectively prohibited by capitalism. And, in any case, as we are all subjects of capitalism, this may be psychically impossible under the present social reality. Realistically, the political economic reality means that screening is not going to be banished any time soon, and is likely to see further, even exponential increases.

However, this leaves open the possibility of small-scale non-institutionally organised resistance to the idea of screening, as a resistance to a particular commodity that is causing great harms, by either refusing to offer this form of care, or campaigning
against it. This would be to act against a vast weight of institutional, professional and public opinion, but it would have the possibility of increasing power over time.

Population anticipatory programmes are always harmful because the tests are never 100% accurate and false positives and overdiagnosis is inevitable. Even the most accurate tests for neonatal metabolic diseases, such as Phenylketonuria, due to a single enzyme deficiency, still have a highly variable positive predictive value, leading to many false positives and sustained parental anxieties (Rydz, 2005). And, given that there is a limited budget (public or personal) this means rationing decisions are already happening, inevitably, and occur either explicitly, or by default.

It may well be that the continuing expansion of this mode of care constitutes one of the greatest threats to healthy living. I appreciate the dilemmas posed by very rare conditions, for example, for which only very expensive treatments produced in small quantities are available, and that society at large seems to favour the ‘rescue’ of individuals in trouble regardless of the cost. But, stopping unsolicited population-based screening would free up monies, and carer labour power to be spent on suffering elsewhere. At the same time it must be noted that stopping proactively offering screening would lead to the sacrifice of the lives of some others, whose lives screening might have prolonged, or who might at least have had a cancer prevented.

So, the refusal to even proactively offer anticipatory diagnostic testing to the asymptomatic is a radically non-interventionist and even a potentially authoritarian stance. This stance would be, ostensibly, in the name of protecting what could be called health, or put differently, the personal eco-biological autonomy of individuals, for example of those that will have been overdiagnosed, and to protect access to care-with-love for the suffering. At the same time such a stance could be criticised as motivated by a desire simply to subvert normative authority, or a transgressive perverse, if misguided, desire to cause harm through inaction, for harm’s sake. I suggest that whilst motivation for critique is always in question, the critique itself stands on its own merits. At the same time a legitimate question arises: could such an authoritarian stance be criticised as a kind of eco-fascism (Glaser, 2019 p7)? At least I would say that this question highlights, in more abstract terms, the always present potential ambivalence between a) attempts to emancipate through non-violence (by not even offering an intervention); and b) the potential fragility (ibid. p12) of this
attempt (for example, in the face of public expectations), which can fall into (symbolic) violence (a prohibition of access to anticipatory diagnostic tests by the asymptomatic). Perhaps a Lacanian response would be that the radically non-interventionist stance can direct the gaze to the law, not in order to invoke the law (for example: ‘Be screened!’, or ‘Make the right decision for you!’) but, instead, to question the law and ask the personal ethical question: ‘What should the law be (for me)?’
References


Conclusion


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