

# ANALYSIS

## ESSAY

# Overdiagnosis: when good intentions meet vested interests—an essay by Iona Heath

The pursuit of longer healthy life has led to more people being labelled as diseased. **Iona Heath** examines the factors behind this paradox and argues that we need to find the courage to resist overdiagnosis and instead accept the inevitabilities of ageing

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Underpinned by webs of financial imperatives and conflicted interests, overdiagnosis and overtreatment have become disturbingly pervasive within contemporary medicine and are now deeply embedded within healthcare systems around the world. They have permeated and polluted the drug and medical technology industries, medical research and regulatory bodies, clinical practice, payment systems, guideline production, and national healthcare systems. They are the cause of an astonishing amount of waste and harm.

The main engine is the medical technology industry, which enables healthcare professionals to investigate more and more minutely and to measure and assign numbers to an ever increasing number of biometric parameters. These numbers are almost always normally distributed along a continuum, with one extreme representing a degree of abnormality that begins to correlate with symptoms and suffering that can be ameliorated or cured by medical treatment. So far, so good. The problem is that a toxic combination of vested interest and good intentions produces continual pressure to extend the range of abnormal, shifting the demarcation point further into the territory previously considered normal. This is encouraged by entrenched belief in such old adages as “prevention is better than cure” and “a stitch in time saves nine.” These ancient sayings are imbibed at such a young age that they seem to assume an almost mythological aura of truth, and we have neglected the popperian imperative of investigating why they might be wrong.<sup>1</sup>

## Symptomless epidemic

In pursuing the supposedly self evident truth, we have, for the first time in history, separated our notions of disease from the human experience of suffering and have created an epidemic of disease without symptoms, defined only by aberrant biometrics. An ever greater proportion of healthcare resources are directed towards reducing these numbers to some fictitious state of normality. In the process, those who are perfectly well

are not only assigned labels that in themselves can be shown to compromise health but are also exposed to treatments with significant adverse effects. Yet, time and time again, politicians are unable to resist the easy attractions of preventive rhetoric; most recently, English health secretary, Jeremy Hunt, instructed general practitioners that they must do more to prevent the health of older patients deteriorating.<sup>2</sup> If nothing else, this serves to distract attention from the government’s failure to meet its own responsibilities for health protection through fiscal and legislative measures,<sup>3</sup> such as promoting greater socioeconomic equity, nurturing vulnerable families, and such policies as minimum pricing for alcohol, and plain packaging for cigarettes.

Extending the range of what is considered abnormal clearly expands markets for pharmaceutical and other interventions, and thereby the possibilities of maximising commercial profit. It also invokes the Will Rogers phenomenon first applied to medicine by Alvan Feinstein and colleagues in 1985.<sup>4</sup> The phenomenon occurs when the range of a diagnostic category is extended. As more and more people previously considered normal are included within the definition of, for example, hypertension, diabetes, or breast cancer, outcomes improve: rates of hypertensive stroke or diabetic foot amputation or breast cancer mortality seem to fall. In this way, extending the definitions of disease and lowering the thresholds for preventive interventions create the illusion of improved population outcomes, while there is no difference at all in the outcomes for affected individuals. Clinicians, health policy makers, and politicians have found it difficult to resist these seductive illusions of progress.

## Ageing is inevitable

The preventing overdiagnosis conference,<sup>5</sup> held at the Dartmouth Institute for Health Policy and Clinical Practice in the US in September, marked the most recent attempt to draw a line in

the sand and to promote more public awareness of and debate about what is becoming an untenable situation, and about what can and will be done about it.

Responses will necessarily be driven by ethics and politics because these are the only real defences that humanity has ever had to confront the abuse of power and money to the detriment of the weak and vulnerable. The whole discipline of medicine has colluded in the wider societal project of seeking technical solutions to the existential problems posed by the finitude of life and the inevitability of ageing, loss, and death, and, as the Swedish writer Sven Lindqvist insists: “It is not knowledge that we lack. What is missing is the courage to understand what we know and draw conclusions.”<sup>6</sup>

The only solutions to these profound existential challenges are to be found in courage and endurance and acceptance of the limits of life. They are to be found in thinking differently and more deeply.

At every level this is a story of unsustainable greed: the greed of those living in the richer countries of the world for ever greater longevity and, most particularly, the greed that drives the commercial imperatives of the pharmaceutical and medical technology industries. The 2012 World Health Organisation *Global Health Expenditure Atlas* reported that countries in the Organisation for Economic Cooperation and Development (OECD) consume more than 80% of the world’s healthcare resources but experience less than 10% of the world’s disability adjusted life years.<sup>7</sup> This must be untenable in terms of both global justice and the world’s capacity. The problem is that where the OECD countries lead, the rest of the world tends to try to follow. Or is pushed to follow.

## Ethics and politics

Overdiagnosis and overtreatment have at least four serious ethical implications. The first is the extent of harm to individuals caused by being labelled as being at risk or as having a disease based entirely on numbers or other aberrant investigations and the unnecessary fear that this can engender, which in itself can undermine health and wellbeing. The second involves the direct relation between overtreatment and undertreatment, because whenever a diagnosis is broadened, attention and resources are inevitably redirected and shifted away from those most severely affected. The third concerns the potential of overdiagnosis and overtreatment to render healthcare systems based on social solidarity unviable because of the escalating costs involved. The fourth is the way in which biotechnical activity marginalises and obscures the socioeconomic causes of ill health.

So what of politics? Back in 1964, the German American political theorist, Herbert Marcuse wrote: “‘Totalitarian’ is not only a terroristic political coordination of society, but also a non-terroristic economic-technical coordination which operates through the manipulation of needs by vested interests.”<sup>8</sup>

This is what large tracts of our healthcare systems have become: a non-terroristic economic-technical coordination that operates through the manipulation of needs by vested interests. It is a perfect description, and the fears of politicians, practitioners, and the public, and the enduring human craving for a predictable future, are making us all into willing participants.

Reviewing George Orwell’s *1984* in 1949, the American critic Lionel Trilling wrote:

He is saying, indeed, something no less comprehensive than this: that Russia, with its idealistic social revolution now developed into a police state, is but the image of the impending future and that the ultimate

threat to human freedom may well come from a similar and even more massive development of the social idealism of our democratic culture.<sup>9</sup>

Arguably, the current ascendancy of medical technology is just such a manifestation of social idealism. War is peace; ignorance is strength; freedom is slavery—and now we have the latest example of Orwellian doublespeak—health is disease.

Trilling continues: “The essential point of *Nineteen Eighty-Four* is just this, the danger of the ultimate and absolute power which the mind can develop when it frees itself from conditions, from the bondage of things and history.”

The sorts of measurement that underpin the imperatives of contemporary medicine—blood pressure, serum cholesterol, bone density, PHQ9 depression score, body mass index, estimated glomerular filtration rate, just to mention a few—are all held to be universally applicable whatever the circumstance of the individual life to which they are applied. They are in Trilling’s words “freed from conditions” and therefore dangerous.

## Loss of the individual

This kind of utilitarian medicine that treats every individual as identical can easily erode the stature and autonomy of patients. More than 20 years ago, David Metcalfe warned general practitioners in the UK:

The WHO definition of health as “complete physical, social, and psychological well-being” says something that we must acknowledge: it is about a person’s potential for living, which is a matter of autonomy and “personal space,” of having room to make choices. These are the concerns of general practice because our professional objectives are wider than the diagnosis and treatment of disease, but we too need to be careful lest diagnostic or therapeutic exuberance in the individual case blind us to our patients’ needs for space and stature.<sup>10</sup>

How much more important is that warning today. We are developing a culture of conformity which pays lip service to autonomy and choice but within which the individual is only really free to make the choice that is approved by the state. It is assumed that once the “healthy choice”<sup>11</sup> is pointed out, everyone will select it and no account is taken of the very differing circumstances and aspirations of different people’s lives.

It has become difficult to question the means because the end of curing and preventing disease is so obviously worthy. Nonetheless, the means are damaging not least because they are so unidimensional and propagate an intensely normative view of what it means to be healthy and indeed what human life should be.

We all need urgently to rediscover what the writer Geoff Dyer has described as “an acute sense of waste as a moral and political issue.”<sup>12</sup> Far too much of what health professionals do and healthcare systems provide is wasteful, futile, and harmful.

The great American thinker William James declared that “doubt and hope are sisters.”<sup>13</sup> In doubt lies all our hope because unless we are prepared to doubt the truth of existing explanations, we will not look for the better ones that could bring us hope. Let’s remember the Danish philosopher Kierkegaard: “It is quite true what philosophy says; that life must be understood backwards. But then one forgets the other principle: that it must be lived forwards.”<sup>14</sup>

Life is lived forwards but understood backwards so that we are obliged to act in advance of our understanding. Doctors are taught and learn to expect benefits from their interventions. Much of the link between cause and effect remains poorly understood,<sup>15</sup> and perhaps we need to be much more rigorous in our expectation of foreseeable harms, and to teach our students to look always for the possibility of harm alongside that of benefit.

Much of what we regard as standard, and even excellent, practice today will eventually be consigned to what the novelist Amitav Ghosh describes as “medicine’s vast graveyard of discredited speculations.”<sup>16</sup> It is so easy to see the mistakes of previous generations, so much more difficult to see the errors of your own.

In a world where it has become acceptable to treat risk factors, however weak, as diseases in their own right, we must learn to resist overdiagnosis. Perhaps one of the best places to begin is remembering the words that James McCormick wrote in the *Lancet* nearly 20 years ago:

Health promotion . . . falls far short of meeting the ethical imperatives for screening procedures, and moreover diminishes health and wastes resource. General practitioners would do better to encourage people to lead lives of modified hedonism, so that they may enjoy, in the full, the only life they are likely to have.<sup>17</sup>

No one was listening then—let’s make sure that we listen now.

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This is an edited version of an address the author gave to the preventing overdiagnosis conference in Dartmouth in September.

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