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ANALYSIS

ESSAY

Role of fear in overdiagnosis and overtreatment—an essay by Iona Heath

Iona Heath argues that doctors and patients need to face up to their fears of uncertainty and death if we are to control overmedicalisation

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In the preface to her influential essay *Illness as Metaphor*, Susan Sontag wrote:

> Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.[1]

Today the kingdom of the well is being rapidly absorbed into the kingdom of the sick, as clinicians and health services busy themselves in ushering people across this important border in ever increasing numbers. Sontag clearly recognises the discomforts of the kingdom of the sick and the extent to which an imposed citizenship there corrodes the joys of life. Yet her essay was first published in 1978, long before the erosion of the kingdom of the well had begun in earnest. With the rise of neoliberal economics, health became a commodity like any other. The exploitation of sickness, and fears of sickness, for the pursuit of profit increased hugely over the subsequent decades, underpinned by the rapid commercialisation of healthcare.

Now, more than three decades later, fewer and fewer of us find ourselves still holding Sontag's good passport and ever more are corralled into the kingdom of the sick earlier than ever, and residency there becomes longer and longer. All this is legitimised by being described as an epidemic of chronic illness, although many of those affected have no symptoms whatsoever. The motivation for the invasion is provided by a toxic combination of good intentions, wishful thinking, and vested interest. The costs—personal, social, and economic—are enormous. The principal weapons deployed are detaching notions of disease from the experience of suffering, broadening the definitions of diseases, turning risk factors into diseases, and, most potent of all, fear.

A terrible synergy of fears will have to be addressed if—working face to face with individual patients—doctors and other healthcare professionals are going to be able to stem the tide. Many clinicians feel helpless in the face of the increasing stampede across Sontag's now very porous frontier, but patients need clinicians courageous enough to reassert the border between the well and the sick so that people make the journey across only when medical care is appropriate and will produce more benefit than harm. There are three separate strands of fear: the existential fears that afflict all of us, the fears of patients, and the fears of healthcare professionals and, perhaps, especially of doctors.

Existential fears

Everyone, to a greater or lesser extent, is afraid of dying. In *Hamlet* Shakespeare provides his famous description of death as: "The undiscover'd country, from whose bourn/ No traveller returns" (Act 3, scene 1).

And it is perhaps this quality of completely uncompromising unknowableness that makes death so terrifying. These lines from Philip Larkin's great poem *Aubade* capture the dread and the horror with visceral intensity:

> Waking at four to soundless dark, I stare.
> In time the curtain-edges will grow light.
> Till then I see what's really always there:
> Unresting death, a whole day nearer now,
> Making all thought impossible but how
> And where and when I shall myself die.
> Arid interrogation: yet the dread
> Of dying, and being dead,
> Flashes afresh to hold and horrify.[2]

Being human, doctors face precisely the same existential challenges of finding meaning in the face of loss, suffering, and

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the finitude of life, and we are no less afraid of our own dying and being dead than anyone else. We have no particular existential aptitude and very little relevant education.[3] Perhaps it is no wonder that we resort so often to our increasingly sophisticated biotechnical means rather than paying real attention to the care of the dying as one of the core purposes of medicine.

Perhaps we should all be reading more Montaigne. In Sarah Bakewell's biography[4] subtitled: "A life of Montaigne in one question and twenty attempts at an answer," the first answer is, "Don't worry about death," and it recounts Montaigne's experience of serious injury some time in 1569 or early 1570. He was 36 years old and over the previous six years had endured the deaths of his best friend, his father, and his younger brother. He was thrown from his horse when another rider collided into the back of him at speed. He seems to have incurred injuries to the head and chest. He had to be carried home a considerable distance and, once he had recovered a degree of consciousness, he seemed to be in considerable distress, struggling to breathe, clawing at his clothes, and coughing or vomiting large amounts of blood. He was not expected to survive. It was at that time, contemplated in retrospect, that he made a surprising discovery. As Sarah Bakewell writes: "he could enjoy . . . delightful floating sensations even while his body seemed to be convulsed, thrashing around in what looked to others like torment."

Montaigne's comforting testimony suggests that the body and mind become to a degree disconnected when death is imminent and, like Montaigne, those who appear to be distressed may, in fact be experiencing his "delightful floating sensations." After he recovered, Montaigne wrote: "If you don't know how to die, don't worry; Nature will tell you what to do on the spot, fully and adequately. She will do this job perfectly for you; don't bother your head about it."

And it seems that Montaigne never worried about death again. Perhaps we shouldn't all be so certain that death is going to be agonising and distressing when we can never actually know.

Fears of patients

The intrinsic existential fears of patients are compounded by the specific fears related to their particular symptoms, and these are sometimes exacerbated by the detail of their family history. Patients are also afraid that their doctors will not understand what they try to describe and that an important diagnosis will be missed or made too late— through laziness, incompetence, or just bad luck. And of course this is fuelled on a daily basis by newspapers, other news media, and, in those unfortunate countries where it is allowed, direct to consumer advertising.

So far so bad—but it is much worse. Hilda Bastian's brilliant cartoon captures everything about the joy sapping consequences of health screening interventions aimed at individuals (figure⇓). For most people the more they know about what they could have wrong with them, the more frightened they become. Preventive rhetoric has taught us to be afraid of what we eat and drink and breathe.

Fears of doctors

The fears of doctors mirror those of patients. Doctors work every day in fear of missing a serious diagnosis and precipitating an avoidable tragedy for one of their patients. In our increasingly punitive societies, with all the easy talk of naming and shaming, doctors are also afraid of being publicly pilloried. Yet clinical work is hedged in by uncertainty on all sides because the application of the generalised truths of biomedical science to the unique context of an individual patient's life and circumstances will always be uncertain. So doctors, perhaps especially young doctors, are learning to be afraid of uncertainty. We order ever more tests to try, often in vain, to be sure about what we are seeing. And because we are afraid that those in the kingdom of the well should perhaps be in the kingdom of the sick, we continually divert resources from the sick to the well so that overdiagnosis inevitably becomes linked with the undertreatment of those already sick. Overdiagnosis of the well and undertreatment of the sick are the conjoined twins of modern medicine.

Patients' fears fuel their doctors' fears and vice versa: especially within healthcare systems that are fragmented and which allow the erosion of continuity of care. It is only within relationships of trust that fear can be in any way contained.

Uncertainty as freedom and resistance

The American philosopher Martha Nussbaum argues that uncertainty and contingency disrupt the gloomy predictability of linear determinism and are what make life worth living:

> The human being who appears to be thrilling and wonderful, may turn out at the same time to be monstrous in its ambition to simplify and control the world. Contingency, an object of terror and loathing, may turn out to be at the same time wonderful, constitutive of what makes a human life beautiful and thrilling.[5]

Only because we do not understand everything and because we cannot control the future is it possible to live.

The British philosopher Stephen Toulmin could be thinking about contemporary healthcare, and the worries and fears of young and inexperienced doctors, when he writes:

> In facing problems about the use of new knowledge for human good, we may ignore the ideal of intellectual exactitude, with its idolization of geometrical proof and certainty. Instead, we must try to recapture the practical modesty of the humanists, which let them live free of anxiety, despite uncertainty, ambiguity, and pluralism.[6]

Toulmin also points out that the Renaissance humanists, who include Shakespeare, Montaigne, Cervantes, and Rabelais, held that: "In practical disciplines, questions of rational adequacy are timely not timeless, concrete not abstract, local not general, particular not universal."

The phenomenon that Petr Skrabanek called "risk factorology"[7] aspires to be timeless, abstract, general, and universal; yet its rise has been exponential, and it has become a potent source of fear among both patients and doctors. Every healthcare professional is now required to consider an ever greater array of potential risks to the patient's health, however well that patient might be feeling. And every responsible and rational citizen is expected to actively seek out and eliminate all possible risks to their future health and to consume medical technologies in order to achieve this aim.

Consider how many of the protocols and guidelines and screening programmes that are driving so much overdiagnosis and overtreatment in contemporary medicine also claim to be timeless, abstract, general, and universal, when we in the discipline of medicine, which will always be practical, need precisely the opposite qualities. Perhaps we should begin to test our decisions and our rational adequacy against these opposite criteria.

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Uncertainty exists in the gap between the territory of human suffering and the map of biomedical science. The task of making the medical map useful to those trapped within the territory of suffering is, and will always be, fraught with uncertainty because of the vast extent and infinite variation of the territory and because of the comparatively rudimentary nature of the map. But the uncertainty and doubt that clinicians experience every day are also what make new knowledge and understanding possible. We have to doubt existing explanations if we are ever to discover better ones.

Yet, however good the map becomes, there will always be limits to how much medicine can achieve (despite the gloss of a million pharmaceutical advertisements). We all need to be as honest about these limits as James McCormick, formerly professor of general practice at Trinity College Dublin:

> Our patients deserve of us accurate diagnosis and appropriate treatment, but when accurate diagnosis is impossible and appropriate treatment unavailable we delude both them and ourselves by using diagnostic labels and prescribing specific treatments. When we as general practitioners are in a position to cure illness, cure is usually readily achieved. But cure only signifies postponement of death: it does not confer immortality. No matter how far medical science advances it can never eradicate human suffering or the fear and fact of death.[8]

The great comfort is the unpredictability of the future. No one knows exactly what will happen tomorrow. We know a lot about probability, but probability is a long way from certainty. People do not always get the result predicted by their lifestyle. Not everyone who smokes or is obese dies prematurely. Conversely, a good diet and regular exercise do not provide complete protection from random disaster. Nonetheless, when death or disease occurs prematurely and unpredictably, the linear rationality in the rhetoric of preventive medicine suggests that someone somewhere must somehow be at fault. And it is this sort of reductive linear reasoning that makes doctors so fearful and invites them always to do more instead of less, however harmful the consequences. The basis of scientific creativity, intellectual freedom, and political resistance is uncertainty. We should nurture it and treasure it and teach its value, and not be afraid of it.

Zygmunt Bauman, emeritus professor of sociology at the University of Leeds, writes:

> To be responsible does not mean to follow the rules; it may often require us to disregard the rules or to act in a way the rules do not warrant. Only such responsibility makes the citizen into that basis on which can be built a human community resourceful and thoughtful enough to cope with the present challenges.[9]

What we need is the courage to always consider the timely, the concrete, the local, and the particular when we care for each individual patient and, if necessary, the courage to disregard the rules. Only on this basis can we build a resourceful and thoughtful healthcare community.

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

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Biography

Iona Heath was a GP for 35 years in an inner London practice in Kentish Town and president of the Royal College of General Practitioners from 2009 to 2012. She wrote a regular column for *The BMJ* until 2013.

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