

EDITORIALS

Death can be our friend

Embracing the inevitable would reduce both unnecessary suffering and costs



Murray Enkin professor emeritus, McMaster University, Canada

Alejandro R Jadad professor and chair, University Health Network and University of Toronto, Toronto, Canada

Richard Smith chair, Patients Know Best, London SW4 0LD, UK richardswsmith@yahoo.co.uk

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“As birth and death actually occur, and our brief career is surrounded by vacancy, it is far better to live in the light of the tragic fact, rather than to forget or deny it, and build everything on a fundamental lie.”

—George Santayana

“Oh build your ship of death. Oh build it! for you will need it.

For the voyage of oblivion awaits you.”

—D H Lawrence

Would you like to die the way your patients do, doctor? We suspect that many of you will answer no. Too many people are dying undignified graceless deaths in hospital wards or intensive care units, with doctors battling against death way past the point that is humane. Because too many doctors have forgotten that death is a friend, people are kept alive when all that makes life valuable has gone. Denying the inevitable comes with a heavy price. We believe that doctors and their patients need to adopt a much more positive attitude to death to reduce suffering and costs.

Death is one of the two great events of our lives. Beyond early childhood we must live with the certain knowledge of death; until medicine began its unwinnable war against death, coming to terms with your death was one of life's most important tasks. *Ars Moriendi* (The Art of Dying) from the early 15th century was a best seller for 200 years, and William Caxton printed 100 copies in 1491. Michel de Montaigne wrote in the 16th century: “Tis the condition of your creation; death is a part of you, and whilst you endeavour to evade it, you evade yourselves.” He urges his readers to “Give place to others, as others have given place to you.” Sir Thomas Browne, the 17th century physician, said “We are happier with death than we should be without it.” Iona Heath, a general practitioner, also writes positively about death: “Without death, there is no time, no growth, no change . . . If we avert our eyes from death, we also erode the delight of living. The less we sense death, the less we live.”¹

THE AUTHORS' DIFFERENT POINTS OF VIEW

Enkin, who is in his late 80s and as he puts it bluntly “statistically closest to death,” has confidence in conversation and education. He thinks that pieces like this, together with others that we have quoted, and—for example, from *BMJ* columnist Des Spence,⁸ will encourage debate and a change in attitude to death

Jadad, a supportive and palliative care physician who is horrified by much of what he sees, thinks something more drastic and urgent is needed to eliminate the iatrogenic suffering fuelled by our denial of death

Smith adds that perhaps those who pay for medicine and regulate it need to act. Ironically, it may be the financial rather than the social and cultural cost of death that will encourage change

But this way of thinking seems to have been largely forgotten or is ignored. Denial, a remarkably powerful force with undoubted benefits, is now the main social and personal response to death. “Death now seems to be optional,” says Ian Morrison, the futurologist. Consequences include huge sums of money being spent in the last months of life, intense pressure to license extremely expensive drugs that extend life for just weeks, and uproar when a dying person is shown on television. Denial of death is a major cause of health costs rising everywhere, but the damage may be much wider than simply to our finances. “The reluctance [to look death in the face] I take to be the root cause of most of our 21st century American sorrows (socioeconomic and aesthetic as well as cultural and political),” writes Lewis Lapham, the American essayist.² Without death every birth would be a tragedy, and sadly we may already be at that point in our overpopulated polluted planet.

Warehouses for the dying

Francis Bacon in the early 17th century was the first to argue that one of the tasks of medicine was to prolong life. He divided medicine into three parts: preservation of health; cure of disease; and prolongation of life—“this,” he wrote, “is a new part, and deficient, though the most noble of all.”³ In fact medicine, in contrast to public health, had little success with prolonging life until comparatively recently. But now that most of us die of complications of chronic incurable diseases, death is very much the territory of doctors. Nobody is dying until a doctor says so, and an increasing number of people die in intensive care units. “I’m running a warehouse for the dying” says an intensive care doctor quoted in an essay on death by the surgeon Atul Gawande.⁴ Only about a fifth of patients emerge alive from American intensive care units.⁴

Are doctors the main villains in the futile fight against death? “Who benefits,” asks Lapham, “from the inventory of suffering gathered in the Florida storage facilities?” Ivan Illich argued that doctors became rich and influential in part because of their supposed ability to hold back death, and by their right to preside over death.⁵ Modern medicine encouraged the decay of traditional means of making sense of death and dying in exchange for an implied but false promise of immortality. Gawande doesn’t mention Illich in his brilliant and chilling essay, but he reaches the same conclusion: “In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die.”⁴ Siddhartha Mukherjee, the oncologist, in his Pulitzer prize winning book on cancer quotes a ward nurse who says: “The resistance to providing palliative care to patients was so deep that doctors would not look us in the eye when we

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► Personal view: Let’s talk about dying (*BMJ* 2011;342:d3018)

► Spotlight: Achieving a good death for all (*BMJ* 2010;341:c4861)

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► Richard Smith: Death becomes fashionable

recommended that they stop their efforts to save lives and start saving dignity instead . . . doctors were allergic to the smell of death. Death meant failure, defeat—their death, the death of medicine, the death of oncology.”⁶ All the evidence shows that the diagnosis of dying is made too late.⁷

Is it possible for us to return to recognising all that is positive about death? If doctors have been the villains of the story might they now become the heroes? Perhaps the *BMJ* would like to promote a roadshow to discuss death; it is likely that many people and many doctors will be ready to make a change.

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the previous three years; all of us expect to die, and ARJ is paid part of his salary to support dying people; all of us have at some time been practising clinicians and benefited in status and salary from people’s fear of death.

Provenance and peer review: Commissioned; not externally peer reviewed.

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The web extra material on bmj.com shows the process that the authors went through to reach the final version of this editorial.

When balance is bias

Sometimes the science is strong enough for the media to come down on one side of a debate



Trevor Jackson magazine editor, *BMJ*, London WC1H 9JP, UK
tjackson@bmj.com

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In his 2010 BBC television series *Wonders of the Solar System*, the physicist Brian Cox made a remark that offended some horoscope lovers. “Despite the fact that astrology is a load of rubbish, Jupiter can in fact have a profound influence on our planet. And it’s through a force . . . gravity.” The BBC received a number of complaints, including one from a viewer who said that Cox made his comment without an “alternative opinion being allowed.” The complainant griped that the programme made no attempt to “consider such questions from the perspective of an astrologer, who draws upon a very different body of observation and knowledge built over thousands of years.” Cox later gave the BBC a statement (which it declined to issue) saying, “I apologise to the astrology community for not making myself clear. I should have said that this new age drivel is undermining the very fabric of our civilisation.”

This tale, which beautifully points up the ridiculousness of always demanding balance in science communication, is told by Steve Jones, emeritus professor of human genetics at University College London, in a report published this year.¹ The BBC Trust commissioned Jones to review the impartiality and accuracy of the BBC’s coverage of science; and although Jones found much to praise, he expresses concern about the BBC’s guidelines on “due impartiality.” These, Jones found, had a distorting effect, creating a sense of equivalence where there was none, and privileging maverick and dissident views so that they appeared as valid as established scientific fact. (This is not to say that established facts cannot be disproved. But the onus is on the claimants to prove or disprove their case within the rigorous paradigms of modern scientific research—witness the current debates on the invariability of the speed of light.)

Jones found that BBC journalists, in their quest for objectivity and impartiality—entirely understandable aims in coverage of politics and arts—risked giving the impression in their science reporting that there were two equal sides to a story when clearly there were not. As Jones says, “There is widespread concern that [the BBC’s] reporting of science

sometimes gives an unbalanced view of particular issues because of its insistence on bringing in dissident voices into what are in effect settled debates.”

The dangers of this approach are clear in journalistic coverage of subjects such as the MMR (measles, mumps, rubella) vaccine—as the *BMJ* has previously shown²⁻³—and climate change. A 2003 study into coverage of MMR showed that the media’s insistence on giving equal weight to both the views of the anti-vaccine camp and to the overwhelming body of scientific evidence exonerating the vaccine from its alleged adverse effects made people think that scientists themselves were divided over the safety of the vaccine, when they were not.⁴⁻⁵ The quest for balance created what Jones and others have called “false balance,” and in the case of the MMR vaccine helped fuel a public health disaster.

The investigative journalist Nick Davies, in his 2008 book *Flat Earth News*—an examination of falsehood, distortion, and propaganda in the world’s media—says that the insistence on balance is one of the factors that stops journalists getting at the truth. “Neutrality requires the packaging of conflicting claims, which is precisely the opposite of truth telling. If two men go to mow a meadow and one comes back and says ‘The job’s done’ and the other comes back and says ‘We never cut a single blade of grass,’ neutrality requires the journalist to report a controversy surrounding the state of the meadow, to throw together both men’s claims and shove it out to the world with an implicit sign over the top declaring, ‘We don’t know what’s happening—you decide.’”⁶

Not every story has two legitimate sides

Another seasoned UK journalist, Malcolm Dean, takes a similar line on balance in his 2011 book *Democracy Under Attack*,⁷ as does the Science Media Centre, in its evidence to the ongoing Leveson inquiry into media ethics.⁸ If journalists will not decide where the truth lies, this puts the onus on readers and viewers; and given that scientists are not always expert communicators, there is a real risk that the anti-science view will hold sway.

Davies's and Dean's position reflects that of the US academics Maxwell T Boykoff and Jules M Boykoff, who have researched the reporting of climate change. In two seminal papers, the Boykoffs identified the journalistic norm of balance—the refusal to privilege the high level consensus that anthropogenic climate change is a reality over the views of right wing mavericks and oil industry funded commentators—as one of the factors that has sown doubt and confusion among the public.^{9 10}

In his recent book *Who Speaks for the Climate?*, Maxwell Boykoff shows that the journalistic norm of balance in news reporting “has served to amplify outlier views on anthropogenic climate change, and concurrently engendered an appearance of increased uncertainty regarding anthropogenic climate science. This, in turn, has entered into an already highly contested arena where it has permeated climate policy discourse and decision-making.”¹¹

Part of the problem is that it takes time for a scientific consensus to emerge, and the media are impatient. Few scientists would nowadays argue that smoking does not cause lung cancer, that the world was created in six days, or that the earth is flat, but that wasn't always the case. Davies shows how the oil industry began mobilising its public relations campaign against the notion of anthropogenic climate change in 1989, years before any scientific consensus could emerge on global warming.⁶

So what is to be done? In the current climate, as media outlets have to produce ever more copy with fewer resources, the outlook is bleak. The BBC hopes that a new stipulation in its editorial guidelines—“due weight,” the recognition that, for example, minority views should not necessarily be given equal weight to the prevailing consensus¹²—and an online training module on the specific

demands of science reporting will help. Steve Jones says he is yet to see any evidence of the difference this can make, but it is a start. Also, researchers themselves should hone their communication skills.

Meanwhile, some science journalism will continue to be weighed in the balance and found wanting.

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Recognising the potential of cities

Cities can contribute to, rather than threaten, a healthier and more ecologically sustainable future



David Satterthwaite senior fellow

Diana Mitlin principal researcher, International Institute for Environment and Development (IIED), London WC1X 8NH, UK

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Cities have never enjoyed a good reputation for health. In many African and Asian cities, health problems and life expectancies are still as bad as in 19th century cities in Europe and North America. Yet other cities have some of the world's highest life expectancies.

Most of the world's cities are now in Africa, Asia, and Latin America. But in Africa and Asia most governments and aid agencies ignore city problems. They fail to notice how many people now live in cities and how bad conditions are for much of the population—in hundreds of cities, a third or more of the population lives in illegal settlements that lack basic services. But it is increasingly evident that well functioning cities are key to wealthier more resilient economies. Rapid economic growth in Brazil, India, and China has been underpinned by successful cities. Cities attract new investment because of economies of agglomeration, including infrastructure and service provision, a large diverse labour force, and sizeable consumer markets.

There is some recognition of how much urban poverty has grown—a large proportion of those who are malnourished and hungry; have poor living conditions; and have high infant, child, and maternal mortality live in cities. But cities also have great potential for the public good. The unit costs of providing piped water, good sanitation, health-care, and emergency services are lowered by density and large population numbers. So too are the costs of providing good schools and the rule of law.

Just as cities provide potential for good health, they also provide opportunities to tackle climate change. Cities are often blamed for being the main drivers of growing greenhouse gas emissions. Yet many cities have low emissions per person, sometimes as little as 1% of that of the largest (mainly North American) emitters.¹ Low emissions are usually a result of weak economies, but some cities with a high quality of life—such as Porto Alegre and Barcelona—have relatively low emissions.¹ Well governed cities where low density urban sprawl is discouraged provide opportunities

to reduce emissions and maintain a high quality of life—for example, by people choosing to walk, bicycle, or travel by public transport rather than use private cars.² Many of those with the highest consumption and high emitting lifestyles do not live in cities.

Many cities are in locations at high risk from climate change—on the coast, places often hit by hurricanes, areas with very high temperatures, and particular districts (mostly low income) that are heat islands. But again agglomeration economies can also help build resilience to these effects. Well governed cities build on a base of existing infrastructure and services and capacities for risk reduction, especially for vulnerable populations.

But the benefits of concentrating people and enterprises can be realised only by competent and accountable city governments and national governments that share resources between richer and poorer areas. Latin America provides evidence for this. Over the past three decades, the proportion of city dwellers with piped water, sewers, and drains has increased dramatically. Although many city dwellers still live in informal settlements, it is much less common for these to be bulldozed. The acceptance of these people as equal citizens has been underpinned by more fundamental political change—the return to democracy, real decentralisation, the introduction of elected city governments, and more participatory governments (including participatory budgeting), all of which are underpinned by pressure from citizens and grassroots organisations. Such experiences are key to social progress and democratic transformation. From the Middle Ages onwards, cities have enabled citizens to come together and define more equitable outcomes and more democratic choices.

Grass roots

Progress is also evident in Asia and Africa. The Thai government’s Community Organizations Development Institute

has shown that living conditions in informal settlements can be transformed by supporting residents to design and implement improvements.³ Across hundreds of cities in Africa and Asia, grassroots organisations including federations of “slum” and shack dwellers are finding new ways to satisfy their own needs, such as developing their own savings schemes, building or upgrading their homes, and improving sanitation. These federations also offer partnerships to local governments, and where local governments respond positively—as in cities in the Philippines, India, South Africa, Zimbabwe, Malawi, Kenya, Uganda, and Namibia—the scale and scope of what can be done increases.⁴

So we have examples of cities where the potential for health and for delinking a high quality of life from high greenhouse gas emissions is acted on. Some cities also have more inclusive and participatory local governments that work with their low income populations, and this could also help improve health and build resilience to climate change. Success in development, health, and climate change adaptation and mitigation depends on a much wider recognition of these potentials, together with the political will to act on them within nations and within each city.

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Three planks of the Pirate Party’s platform that should matter to doctors

Reform of copyright law, respect for patients’ right to privacy, and the abolition of drug patents



Waldemar Ingdahl science journalist, Valhallavägen 141, 115 31 Stockholm, Sweden waldemaringdahl@gmail.com

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Now almost six years old, Sweden’s Pirate Party has inspired Pirate parties in several European countries, including the UK (www.pirateparty.org.uk/).¹ The party gained two of Sweden’s 18 seats in the European Parliament in the 2009 elections (winning 7.1% of the vote), and this September its German sister party gained seats in Berlin’s state parliament. Although the party was initially concerned with file sharing, it has expanded its focus to include three areas that are especially relevant to doctors: reform of copyright law, respect for patients’ right to privacy, and the abolition of drug patents.

The Pirate Party is critical of the copyrighting of scientific articles and anything else that reduces their accessibility because it believes that knowledge has intrinsic value. The reform of copyright law could dramatically

speed up the rate of discovery in many disciplines and change the scientific process radically. Similarly, researchers will need to rise above their petty rivalries and be prepared to share their data with others. The internet provides tools to facilitate this.

Many large organisations that fund or host research are now mandating that the results of this research be made “open access,” and many journals have adopted revenue models where the authors (or their employers) pay to enable this to happen. Open access journals such as *PLoS Biology* and *PLoS Genetics* are already among the most prestigious in their field. Once the contents of scientific monographs have also been made available, the Pirate Party dream that publicly funded science should be open science will have become a reality.

