Ivan Illich

L Levin

He lived his own testimony

Scott-Samuel offers a clear and cogent memoir of Illich's contributions to our perspective on medicine in society.[1] The brevity of his memoir should not, and does not, suggest that Illich dealt merely a glancing blow to the negatives in medicine's dominance in matters of health. His thinking pried open the historically impenetrable vault of true belief that medicine is above critique, particularly by those who are not ''qualified.'' Illich clearly stunned the establishment with his powerful and often epigrammatic volleys at medicine's hegemony regarding all-things-health, its often arrogant protectionism, and its failure to deal forthrightly with its shortcomings.

Scott-Samuel's memoir helps us see Illich's themes change to be sure, but they seem to be less evolutionary (re fundamental values, etc) than expansive—that is, more inclusive of medicine's capacity to incorporate changes in society's interests (and concerns) about health. Illich sensed, for example, the emergence of a powerful new ''market'' for achieving health and wellbeing and medicine's quick response to incorporating these profitable dimensions into medical practice. More recently, Illich seemed to be warning that medicine was pathologising health in order to establish itself as the essential resource for promoting health. Scott-Samuel rightly emphasised Illich's concern about the obsessive pursuit of a healthy body. Do we know anything at all about Illich's reaction to the emerging thesis that health is largely determined by social and economic factors and forces well beyond medicine's domain of influence? This, one might guess, could render his early concerns about the medical nemesis less ominous.

I would like to add to Scott-Samuel's memoir a comment regarding Ivan Illich as a person, a personality framed by his diverse cultural experiences, education as a priest, and his working style (and work with associates like John McKnight). He was such an extraordinarily complex, multi-levelled, entertaining, provocative and occasionally irascible character! For me, it is impossible to separate Illich the scholar from Ivan the social person. One informed the other. He truly lived his own testimony!

I knew and admired his special qualities of mind and spirit and also glimpses, just glimpses, of his private side when we were together briefly in Copenhagen and New Haven (where he stayed at my home). Also, there were several times when we shared a speaking platform. These constitute a rather narrow pedestal upon which to make any insightful observations of Ivan beyond noting that he had a remarkable talent for seeing beyond the limits of our ordinary, predictable analyses of social issues. He would turn things upside down and shake well, letting new perspectives fall out, sometimes in an orderly way and sometimes in a jumble. No doubt about his shock appeal. He knew how to get your attention and to force debate, which, in turn, begat more debate. And so the intelligence began to churn, leaving some perplexed and others never to be the same again. I was in the second group.

Much has been said about Ivan's intellectual contributions, so I can add little. We agreed more often than not, especially about what we now acknowledge as the important role of social capital.

I think it is necessary, while we stand in awe of his many gifts, that we remember that Ivan had his human side, sharing many traits common to us all. He knew how to enjoy every day and to help those around him not to doze off in the face of the joy of living. As far as I know, Ivan never wore a watch, which he called a ''gauge,'' and believed needlessly forced an artificial structure on our lives. But he would ask those ''gauge bearers'' around him many time related questions, for example, when a plane is to depart, how much time before a lecture, when is he expected to be at a meeting, how long is it to the train, etc. Ivan was full of seeming contradictions, but they were really set up to turn our minds around. He despised linear thinking, and worked to rid us of it whenever and however he could.

By all reports, and certainly by the public image Illich projected, his lifestyle was simple, almost spartan. But he had his moments that revealed his pleasure in some of life's more plebian joys. One such moment took place in a Copenhagen supermarket where Illich joined me in shopping for dinner to be prepared for him after a talk. He insisted initially that ''a simple potato'' would suffice, but when encouraged to add a few other items, he did so with gusto and with a penchant for choice foods and wines! He revealed to me then and on several other homey occasions that when the spotlight was not on him as a scholar-performer, he thoroughly enjoyed his role as a ''family member.''

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REFERENCE

1 **Scott-Samuel A**. Less medicine, more health: a memoir of Ivan Illich. *J Epidemiol Community Health* 2003;**57**:935.

Ivan Illich

Nemesis, Sisyphus, and a contribution from the medical humanities to health research

R H T Edwards

Nemesis or Sisyphus?

The death last year of Ivan Illich is an opportunity for us to reflect on his controversial ''Nemesis'' challenge in 1974 that too much dependence on modern medicine is harmful to the health of the individual and society.[1] It followed the challenge by Archie Cochrane[2] for evidence of the effectiveness of treatment offered by doctors. Both these challenges were largely unheeded at the time. Medical science progressed much as analysed in the book *Little Science, Big Science and Beyond*.[3] Now we are well into the uncertainties of De Solla Price's ''beyond'' in what Beck calls the ''risk society'',[4] with all that means for fear of unknown risks and incurable diseases. Medical science is indeed making health care more powerful and successful than ever, but the potential for harm, as iatrogenic disease and medical accidents (what Illich identified as direct medical harms) is also greater.[5]

In admiration of the success of the Cochrane Collaboration in catalysing the current ''Evidence Based Healthcare'' movement, I ventured to suggest an ''Illich Collaboration''[6] to assemble comparably reliable evidence to prevent direct medical harms. However, Illich also pointed to the indirect harms that render people less able to cope with the usual challenges of living and dying. The tendency that the more health care given to a population the greater its demand for care (the ''Sisyphus syndrome''—after the Greek myth of Sisyphus, who was condemned to roll stones up hill for ever…). This is because modern health care leads to increased longevity[7] with more opportunity to accumulate chronic diseases—needing health care. An econometric analysis[8] suggests that this Sisyphus syndrome may not be as great a problem as previously thought but that needs to be confirmed.

Beyond this chronic disease related Sisyphus syndrome is another that depends on whether or not a healthcare system should be regarded as a service industry. If so there are clear implications that encourage demand. As originally envisaged by the founding fathers of the National Health Service in the UK, a free healthcare system should result in a healthier society, and there would be less demand. This is clearly not the case and demand for medical care continues unabated. Demand for complementary and alternative therapies is also great.[9] Edward Shorter[10] attributes demand to a ''pas de deux'' between doctors and patients, which today we see as consumer demand for personal service and choice fuelled by the ever widening taxonomy of disease and professional differentiation (that is, more diseases and more experts). The distinguished medical historian Roy Porter, who also died last year, warned[11] that medical consumerism, like all other forms of consumerism, is designed to be unsatisfying. Central to such medical consumerism is autonomy—which from the ethical viewpoint, is defined as the ''right to decide whether or not to undergo any medical intervention even when a refusal may result in harm to themselves or in their own death''.[12] While the ''no treatment now'' option always needs to be considered, the world's economic and political topography now may dictate that fewer choices in self determination are possible than when Illich wrote his warning, and dependence on a healthcare system may for many have to be the price of ''staying the course''. This is difficult but it is perhaps time to change the emphasis from the economics of health care to exploring the economics of health.[13] Evidently social reform cannot replace health care but it deserves further evaluation as separate determinant of health and wellbeing.[7]

Whether or not we can learn to live with less dependence on drugs, therapies, and professional advisors, though desirable in the interest of independent ''health'', is however doubtful. To attempt to do so would need to take us ''beyond'' contemporary healthcare strategies to explore the varied heritage of human experience of life and death. Here the recently established discipline of medical humanities may help. Leo Tolstoy (in *The Death of Ivan Iliych*[14] describes graphically Ivan's final illness in 19th century Russia as he achieves a vision of equanimity or redemption in a peaceful death, portrayed as a triumphal fulfilment of his life.

Can we avoid Illich's ''Nemesis''? I hope so—research may throw more light on some positive characteristics of ''health'' (for example, resilience, courage, altruism, good humour, etc). Specifically, research might focus on how to develop the mental ''toolkit'' for coping with disability, such as remarkably reported recently,[15] the ''dis-eases'' of life and how to face death with autonomy and something approaching equanimity.

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Key points

- Is health care a ''service industry''?
- Voluntary choice of the ''no treatment now'' option?
- Hypothesis generation from the medical humanities for research into the positive attributes of health.

Policy implications

- If health care shares features with service industries, what are implications for demand generation?
- Can emphasis on patient autonomy and avoiding harm lead to voluntary demand reduction?
- Can more research into generic healthcare solutions help patient/user collaboration and autonomy?

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REFERENCES

1 **Illich I**. Medical nemesis [reprint]. *J Epidemiol Community Health* 2003;**57**:919–22.

2 **Cochrane A**. *Effectiveness and efficiency: random reflections on health services*. London: Nuffield Provincial Hospitals Trust, 1972.
3 **De Solla Price DJ**. *Little science, big science…and beyond*. New York: Columbia University Press, 1986.
4 **Beck U**. *Risk society: towards a new modernity*. London: Sage, 1992.
5 **Sharpe VA**, Faden AI. *Medical harm: historical, conceptual, and ethical dimensions of iatrogenenic illness*. Cambridge: Cambridge University Press, 1998.
6 **Edwards RHT**. Is it time for an Illich collaboration to make available information on the harms of medical care? *BMJ* 1999;**318**:58.
7 **Bunker JP**. Ivan Illich and the pursuit of health. *Journal of Health Service Research and Policy* 1997;**2**:56–9.
8 **Zweifel P**, Steinmann L. The Sisyphus syndrome in health revisited. http://perso.wanadoo.fr/ces/Pages/english/PS14-1.pdf. (accessed 3 Jun 2003).
9 **Eisenburg DM**, Kessler RC, Foster C, *et al*. Unconventional medicine in the United States. *N Engl J Med* 1993;**328**:246–52.
10 **Shorter E**. *From paralysis to fatigue: a history of psychosomatic illness in the modern era*. New York: The Freedom Press, 1992:xi.
11 **Porter R**. *The greatest benefit to mankind: a medical history of humanity from antiquity to the present*. London: Harper Collins, 1997:710–18.
12 **GMC**. *Seeking patients' consent: the ethical considerations*. London: General Medical Council, 1999:2.
13 **Edwards RT**. Paradigms and research programmes: Is it time to move from health care to health economics? *Health Econ* 2001;**10**:625–49.
14 **Tolstoy L**. *The death of Ivan Ilyich and other stories*. London: Penguin Books, 1960:101–61.
15 **Colchester J**. *A life worth living: abilities, interests and travels of a young disabled man*. Nantwich: Greenridges Press, 2003.

Ivan Illich

Ivan Illich and medical nemesis

J P Bunker

The appropriation of health

In 1974 Richard Smith, the editor of the *British Medical Journal*, and I each attended lectures by Ivan Illich. Smith, then a medical student in Edinburgh, heard him claim that ''the major threat to health in the world is modern medicine.'' While a visiting professor in Boston that same year I heard him make the same claim. Smith recalls that listening to Illich was ''the closest I ever came to a religious experience''.[1] I had a somewhat different reaction, one tempered by the exchange between Illich and a medical student after his lecture. The student, raising his hand, said ''but Dr. Illich, I just want to help sick people'', to which Illich replied with a sneer that ''you're no better than the Nazi doctors.'' Smith's reaction was to drop out of medical school (for three days). Mine was disgust.

Looking back today I realise that I misunderstood what Illich was up to. I subsequently read *Deschooling Society*, in which he attacked the educational system for serving to indoctrinate the young in the overproduction of goods to satisfy the consumer society. Much the same theme reappears towards the end of *Medical Nemesis*, in which he wrote that ''like school education and motor transportation, clinical care is the result of a capital-intensive comodity production'' in which the patient as an individual becomes a technological product. He argued that medicine ''constitutes a prolific bureaucratic program based on the denial of each man's need to deal with pain, sickness, and death''.

As an anaesthetist Illich's pronouncement of the need to experience pain is of special interest to me. He wrote, in a chapter entitled *The Killing of Pain*, that the medicalisation of pain ''has rendered either incomprehensible or shocking the idea that skill in the art of suffering might be the most effective and universally acceptable way of dealing with pain.'' Illich traces his views on pain to those of the church and of most religions, for which historically ''it was unthinkable that pain ought not be suffered, alleviated, and interpreted by the person afflicted, but that it should be—ideally always—destroyed through the intervention of a priest, politician, or physician.'' The ''opportunity for purification, penance, or sacrifice'' was to be welcomed.

Illich believed that ''better health care will depend not on some new therapeutic standard, but on the level of willingness and competence to engage in self-care'', and he defined self-care broadly as consisting of ''personal activities [that] are shaped and conditioned by the culture in which the individual grows up: patterns of work and leisure, of celebration and sleep, of production of food and drink, of family relations and politics''. In *Tools for Conviviality*, written three years before the publication of *Medical Nemesis*, Illich described this ideal state as an ''autonomous and creative intercourse among persons within their environment… individual freedom realized in interpersonal interdependence and, as such, an intrinsic ethical ideal.'' He called this a state of conviviality, and his notion of its health enhancement is remarkably in tune with current views of the impact of the social environment on health.

Illich's attack has been largely ignored by the medical profession and there is little if any evidence that it has affected the continuing growth of the medical establishment. But *Medical Nemesis* has not been forgotten. It was reprinted in 1990 by Penguin and in 1995 by Marion Boyars. The latter, retitled *Limits to Medicine*, includes a new preface, and in it he makes his purpose crystal clear. ''I used medicine as a paradigm for any mega-technique that promises to transform the *conditio humana*. I examined it as a model for any enterprise claiming, in effect, to abolish the need for the art of suffering by a technically engineered pursuit of happiness.'' In the preface Illich made the extraordinary and revealing statement that '' emphatically, I do not care about health''. Should there be any doubt as to the sincerity of this statement or of his views on the medical enterprise, how he responded to his own ill health is instructive. After Illich's death in December, 2002, an obituary in the London *Independent* reported that when he was ''diagnosed with cancer in 1983, he refused all treatment…As the tumour on his cheek became more prominent and painful and subject to epileptic attacks, he refused to accept the diagnosis imposed by the doctors. 'I am not ill, it's not an illness', he declared. 'It is something completely different–a very complicated relationship.'''

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REFERENCE

1 **Smith R**. Review of limits to medicine. Medical nemesis: the expropriation of health. *BMJ* 2002;**324**:923 [This is an abridged version of the review that appears in this issue on page 928].

Ivan Illich

Limits to medicine. Medical nemesis: the expropriation of health

R Smith

An abbreviated version of this review has been published in the *BMJ*.*

The closest I ever came to a religious experience was listening to Ivan Illich. A charismatic and passionate man surrounded by the fossils of the academic hierarchy in Edinburgh, he argued that ''the major threat to health in the world is modern medicine.'' This was 1974. He convinced me, not least because I felt that what I saw on the wards of the Royal Infirmary of Edinburgh was more for the benefit of doctors than patients. I dropped out of medical school that day. Three days later I dropped back in again, unsure what else to do. Now I'm the editor of the *BMJ*, which is ironic. Having deserted medicine, I've become a pillar of the British medical establishment (yes I am, like it or not).

I devoured both *Medical Nemesis* and *Limits to Medicine*,† and now I've reread the latter—for the first time in 25 years. The power of the book is undiminished, and its prescience seems remarkable. What was a radical polemic in 1974 is in some sense mainstream in 2002. Medicine does seem to have overreached itself and some reining in will benefit not only patients but also doctors.

Health, argues Illich, is the capacity to cope with the human reality of death, pain, and sickness. Technology can help, but modern medicine has gone too far—launching into a godlike battle to eradicate death, pain, and sickness. In doing so, it turns people into consumers or objects, destroying their capacity for health.

Illich sees three levels of iatrogenesis. Clinical iatrogenesis is the injury done to patients by ineffective, toxic, and unsafe treatments. The book has extensive footnotes that draw from a far wider range of sources than most medical books. Illich is equally at home with the *New England Journal of Medicine* and medieval German texts, making him a formidable opponent for the contemporary doctor who might dispute his conclusions. Evidence based medicine is described in these pages, 20 years before the term was coined. Illich also points out that 7% of patients suffer injuries while hospitalised. Yet only in the past few years and in a few countries have doctors begun to take patient safety seriously.

Social iatrogenesis results from the medicalisation of life. More and more of life's problems are seen as amenable to medical intervention. Pharmaceutical companies develop expensive treatments for non-diseases. Health care consumes an ever growing proportion of the budget. In 1975 the United States spent $95 billion on health care, 8.4% of its gross national product—up, Illich noted, from 4.5% in 1962. In 2001 it was $1424 billion, 14% of GNP. Predictions published this month suggest it will be $2815 billion, 17% of GNP by 2011. Can this be sensible?

Worse than all of this for Illich is cultural iatrogenesis, the destruction of traditional ways of dealing with and making sense of death, pain, and sickness. ''A society's image of death,'' argues Illich, ''reveals the level of independence of its people, their personal relatedness, self reliance, and aliveness.'' For Illich ours is a morbid society, where ''through the medicalisation of death, health care has become a monolithic world religion…Society, acting through the medical system, decides when and after what indignities and mutilations he [the patient] shall die…Health, or the autonomous power to cope, has been expropriated down to the last breath.'' Dying has become the ultimate form of consumer resistance.

Illich's book is more polemic than analysis and should be read as such. The rhetoric is intoxicating, and I can see why Illich captured my soul all those years ago. Illich was a Catholic priest before he became a critic of industrial society, and the story he tells reeks of ''the fall of man.'' Romantically, Illich seems to hanker after ''the noble savage,'' and most readers of his book will never have known such a person and may be sceptical that he has ever existed. Much of life before modern medicine looked nasty, brutish, and short, and have not most people offered the choice opted for the comforts of modern medicine?

It's the ultimate book reviewer's cliché to say that every doctor and medical student should read this book, but those who haven't have missed something important. When sick I want to be cared for by doctors who every day doubt the value and wisdom of what they do—and this book will help make such doctors.

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*See *BMJ* 2002;**324**:923.
†Limits to medicine. Medical nemesis: the expropriation of health. By Ivan Illich. (Marion Boyars, £2.50, pp 294, ISBN 0-7145-2513-8).