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Patient empowerment and the dilemmas of late-modern medicalisation

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In *Medical Nemesis*,¹ perhaps the most influential definition of medicalisation ever written, historian-philosopher Ivan Illich argued that by overextending its scientific and cultural authority, modern medicine had itself become a threat to health, a fount of “doctor inflicted injuries” and “iatrogenic disease”.¹ Although Illich’s 1975 book focused mainly on the role of the medical profession in creating these problems, he suggested that the ill effects of medicalisation might well be reversed by the actions of a long “passive public”, now beginning to recover its “will to self-care”.¹ The deepening crisis of modern medicine presented new opportunities for “the layman effectively to reclaim his own control over medical perception, classification, and decision-making,” a “laicisation of the Temple of Aesculapius” that Illich believed held great promise for the reform of modern medicine.¹

Read afresh in 2006, Illich’s emphasis on laicisation seems remarkably prescient in some ways. Since the 1970s, patient activists in the USA and Europe have aggressively asserted their claims to be regarded as experts on their own illnesses and to play a more active part in health-care decision-making. Patient initiatives have resulted in monumental changes in the practice of medicine, including the legalisation of abortion, living wills, hospice care, hospital bills of rights, lumpectomies, experimental clinical trials, and expanded access to a vast array of consumer health information, to name only a few examples. Although many physicians initially resisted the idea of increased patient participation, lately they have become reconciled to, sometimes even enthusiastic about, the idea of the patient as partner. In developed countries, patients are now expected to take an active role in their care, and to be treated as important stakeholders in policy debates.²

Yet contrary to Illich’s 1970s optimism, increasing the role of patients in clinical decision-making has not been the solution for the many problems that beset late modern medicine in developed countries. The advent of patient-centred medicine has come at such a troubled point in history that its achievements are in danger of being negated. Although patient initiatives have secured the expansion of some kinds of choices and safeguards, especially for the educated and affluent, they have been

offset by growing demands for cost containment and market discipline that have limited the autonomy of both physicians and patients. Expectations of doctor-patient partnerships have been complicated not only by persistent asymmetries in the knowledge and power bases of the two participants, but also by contradictory pressures to limit costs yet also to secure the best and usually most expensive treatments.³

In the face of such complications, to revert to an oversimplified cast of heroes and villains, and to replace the doctor blaming of the 1970s with patient blaming in the early 2000s, is tempting. Ignorant, irrational patient-consumers provide an easy explanation for the persistence of problems: they refuse to believe in the truths revealed by science or economics, they resist paying what services are worth; they seek the wrong services (Botox, breast implants) and ignore the prudent action (smoking cessation, healthy diet). In the new era of collaborative medicine, patients have nowhere to hide.

Perversely, whereas patient choices are often denounced as expensive and irrational, claims to be acting on behalf of patients’ true interests have become so promiscuously asserted as to be almost meaningless. Stakeholders with diametrically opposed policy positions present themselves as the patients’ best friend: the drug company justifying its use of direct-to-consumer advertisements, and the consumer groups calling for their elimination; the insurance companies imposing benefit limitations, and the doctors and patients who challenge them; the policy camp arguing for medical savings accounts, and the policy camp opposing them. As all the major players in current policy debates justify their positions in the language of patient empowerment, that language has become essentially bankrupt.

Yet for these very reasons, we need to scrutinise the conception of patient-centred medicine in an era of perpetual health-care crisis. Returning to a pre-1970 model of paternalism is simply impossible; the only way forward lies in improving on the collaborative models that have emerged in clinical and policy settings over the past two decades. Future debates need to focus not only on the values but also on the processes by which patients’ interests are defined, measured, and protected.

Recent social-science scholarship can be helpful on these points. Since the 1970s, medicalisation has been re-envisioned, not as a top-down imposition of professional or social control, but rather as a continuous dialogue between doctors and patients. The new scholarship assumes that these dialogues will be complex and often contentious. As sociologists Williams and Calman⁴ have noted, increasing education and diffusion of health information have so democratised knowledge and pluralised “knowledge claims and systems of expertise,” that claims to have unassailable scientific truths or evidentiary standards are impossible to make. The late 20th century politics of personal identity, with their legitimisation of multiple health statuses—defined by gender, race, ethnicity, sexual orientation, disability, etc—have made differentiating the authentic from the inauthentic need more difficult. Finally, the highly fraught process of making health choices takes place within a highly competitive economy in which powerful business interests have a major stake in influencing those choices. A much studied example of this influence is the effect of modern drug marketing and advertising campaigns on physicians and patients.⁵

The difficulties inherent in late modern processes of judging and choosing are evident in critiques of evidence-based medicine. During the past decade, evidence-based medicine has gained great popularity as the new scientific gold standard, a standard seemingly protected both from bad science and undue commercial influence. Indeed, evidence-based medicine is a beautiful example of the kind of late modern rationality described by sociologists such as Anthony Giddens and Ulrich Beck:^{6,7} a technologically advanced approach to therapeutic choice that attempts to minimise risk by better understanding and predicting it. As such, evidence-based medicine presents both the strengths and weaknesses that social scientists have identified in late modern risk assessment.

The problem of where the patient’s judgment fits in the process of arriving at practice guidelines is a case in point. Although evidence-based medicine advocates laudably took improving patient care as their goal, the methods they use to define and measure outcomes remained firmly in specialist hands. The collaborations set up by Cochrane and other similar groups were partnerships between researchers and clinicians, not doctors and patients. In the pyramid figures often used to show the reliability of medical information, sources close to the patient inevitably tended to be at the bottom.⁸ And as patient advocates soon noted, the most easily measured aspects of physiological change and therapeutic efficacy did not necessarily capture the markers of recovery that patients themselves deemed most important. Best practices presented as physician dicta from on high, without patient involvement in their determination or dissemination ran the risk of becoming just another form of medical imperialism.

In response to these criticisms, evidence-based groups have expanded the notion of collaboration to include patients and consumers; for example, in 1995, the

Cochrane Collaboration set up its Cochrane Consumer Network,⁹ which commissions consumer comments on Cochrane reviews. Yet the challenges to making these collaborations work remain daunting. As Hilda Bastian noted in *Cochrane news*¹⁰ in 1998, “Involving consumers is something that is easier said than done—especially when everyone’s time and resources are stretched.” Lay acceptance of evidence-based guidelines remains problematic, in that their credibility is dependent on statistical expertise about relative and absolute risk and risk reduction that is beyond many people. Negative results based on large-scale studies do not necessarily dampen individual patients’ hope that for them, a particular therapy might work. In the clinical encounter, both doctor and patient bring unconscious and conscious beliefs and expectations that do not easily fit into the model of rationality assumed by the evidence-based medicine approach. For example, as Jonathan MetzI’s work shows, the choice of medication holds complex symbolic meanings for both doctor and patient that are rarely considered in guidelines for rational prescribing.^{11,12}

More time and money spent on assessing research studies, and investing in the latest information technology to convey their results to clinicians, will not resolve these sorts of questions. The only hope is to confront these challenges and improve the processes of informed choice, to combine the scientific spirit of a Cochrane Collaboration with the psychological proficiency of a Balint group. These are challenges best resolved not at the time of the individual clinical encounter, but rather when practice guidelines are produced, with processes that give economically disinterested advocates for physicians and patients time to consider them carefully.

In the USA, where medicine is highly specialised, exchanges between medical specialty and advocacy groups, while often confrontational, have profoundly altered the course of treatment, as in the HIV/AIDS epidemic and the treatment of breast cancer.^{13,14} The field of mental health offers a particularly striking example in which collaborative interactions between patient and consumer groups, policymakers, and clinical researchers have produced good results.¹⁵ The challenge remains to combine these networks into larger political alliances that move beyond the prevention and treatment of single diseases to a more sweeping set of reforms.

Collective collaborations, in which intermediary groups strive to produce general guidelines, grounded in good science, vetted by both medical and patient representatives, and forged behind firewalls that minimise for-profit market influences, seem the more promising route for the future. History suggests that this work will be difficult and frustrating. But it offers the best hope for fully realising the benefits of collaboration between doctor and patient, as worthy a goal in 2006 as it was in 1970.

Conflict of interest statement

I declare that I have no conflict of interest.

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Beyond medicalisation

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Medicalisation has become a cliché of critical social analysis. It implies something suspect when a problem is created or annexed, in whole or in part, by the apparatus of medicine. Critiques of the ways in which doctors have extended their empire have become part of everyday and professional debate. Such critiques have contributed to the part deprofessionalisation of medicine. Nowadays, the power of doctors is constrained by the shadow of the law, the apparatus of bioethics, evidence-based medicine, and patients’ demands for autonomy to be respected, their rights to health satisfied, their injuries compensated. The focus of critique has turned to the methods used by drug companies in search of markets and profits. There is, no doubt, much to criticise. Yet medicalisation has had an even more profound effect on our forms of life: it has made us what we are.

Since at least the 18th century in developed countries, medicine played a constitutive part in “making up people”.¹ It was in part through medicine that the human being became a possible object for positive knowledge—a living individual whose body and mind could be understood by scientific reason. Medicine was perhaps the first scientific knowledge to become expertise, in which authority over human beings derived from claims to scientificity. Medicine was entwined with new ways of governing people, individually and collectively, in which medical experts in alliance with political authorities tried to manage ways of living to minimise disease and promote individual and collective health. Medicine was linked to the secularisation of ethical regimes, as individuals came to describe themselves in the languages of health and illness, question themselves against criteria of normality and pathology, take themselves and their mortal existence as circumscribing their values. The history of medicine has thus been bound up with the history of the different ways

in which human beings have tried to make ourselves better than we are.²

Immediately two cautions must be entered. The we needs unpacking by age, class, race, nationality, sex, and more: some people are more medically made up than others—women more than men, the wealthy differently from the poor, children more than adults, and, of course, differently in different countries and regions of the world. Furthermore, medicine itself needs to be decomposed. The technologies of the operating theatre are not those of general practice, or epidemiology, or public health medicine, or health promotion. Medicine has no essence, be it epistemological (there is no single medical model), political (the power of medicine cannot be reduced to social control or the management of social problems), or patriarchal (medicine and medics do not merely seek control over women and their bodies). Medicine is not a single entity: clinical medicine is only one component among many ways in which individual and group life have been problematised from the point of view of health. And medical knowledge, medical experts, and medical practices play very different parts in different locales and practices. Here I distinguish three dimensions through which medicalisation has made us the kinds of people that we are.

Medical forms of life

The practices of medicine have modified the very life form that is the contemporary human being. Sewage systems, regulated cemeteries, purified water and food, dietary advice, and the general sanitisation of human existence, domestic life, public space, working environments, all in part under the aegis of medical authority, have altered physical appearance—height, weight, posture, capacities—longevity, morbidity, and much more. These practices have changed the relations that human beings have with